A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS

MODULE 1:

ALZHEIMER'S DISEASE AS A PUBLIC HEALTH CRISIS

alzheimer's association®

CDC
Centers for Disease Control and Prevention

EMORY
ROLLINS SCHOOL OF PUBLIC HEALTH

Emory Centers for Training and Technical Assistance

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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.

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LAYOUT OF MODULE 1 FACULTY GUIDE

This guide is laid out in the following sections:

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

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

HOW TO USE THE MATERIALS

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

STUDENT ENGAGEMENT OPTIONS

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

DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

- 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

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TALKING POINTS:

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

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

SLIDE 3:

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 Crisis[1]

- 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.

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[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

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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=yJXTXN4xrI8

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[4]Alzheimer'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 Disparities[7]

- 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.

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[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 Deaths[8]

- 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**.

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[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 Epidemic[12]

- 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**.

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[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 & Medicaid[15]

- 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.

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[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.

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[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 Workforce[19]

- 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 Caregivers[20]

- 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 Caregivers[21]

- 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: Challenges[22]

- 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: Shortage[26]

- 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**

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[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: Challenges[29]

- 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.

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[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 2020[30]

- 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

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TALKING POINTS:

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

A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS

ALZHEIMER'S DISEASE –
A PUBLIC HEALTH CRISIS

alzheimer's association

CDC Centers for Disease Control and Prevention

EMORY Rollins School of Public Health | Emory Centers for Training and Technical Assistance

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

2

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.

3

ALZHEIMER'S – PUBLIC HEALTH CRISIS

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

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

4

WHAT IS DEMENTIA?

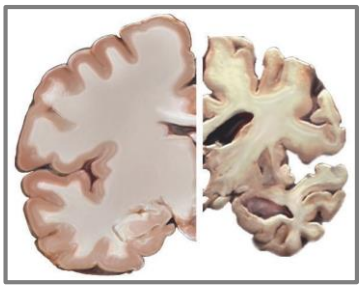
- General term for decline in mental ability severe enough to interfere with daily life
- Affects memory, thinking ability, social ability
- Many dementias are progressive

[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.*

5

WHAT IS ALZHEIMER'S DISEASE?

- 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



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[4]Alzheimer'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.*

SCOPE OF THE EPIDEMIC

ALZHEIMER'S DISEASE – A PUBLIC HEALTH CRISIS

7

SCOPE OF THE EPIDEMIC (U.S.)

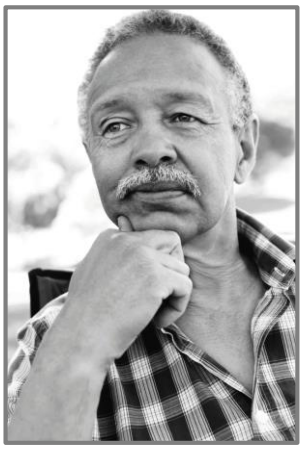
- Over 5 million adults
- 1 in 9 adults age ≥65
- 1 in 3 adults age ≥85
- 2/3 are women

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

8

HEALTH DISPARITIES

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



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

9

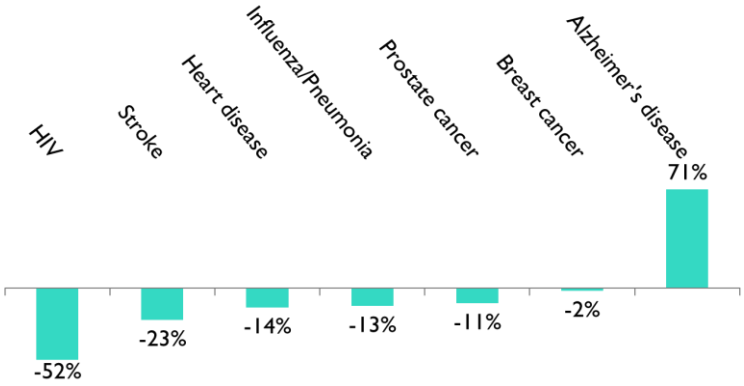
ALZHEIMER'S DEATHS

- 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

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

10

CHANGES IN SELECTED CAUSES OF DEATH (ALL AGES) BETWEEN 2000-2013



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

11

GROWING EPIDEMIC

- 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

[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.*

12

WORLDWIDE EPIDEMIC

- 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

13

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

FINANCIAL BURDEN

ALZHEIMER'S DISEASE – A PUBLIC HEALTH CRISIS

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FINANCIAL BURDEN: U.S. & WORLDWIDE

- 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

15

DISCUSSION QUESTION

What are Medicare and Medicaid?

16

MEDICARE & MEDICAID

- 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

17

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

ALZHEIMER'S: MEDICARE & MEDICAID

- 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

18

[16]Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures.*
[17]Alzheimer's Association. (2015) *Costs of Alzheimer's to Medicare and Medicaid*.

ALZHEIMER'S: PROJECTED COSTS (2050)

- 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

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

CARE BURDEN

ALZHEIMER'S DISEASE – A PUBLIC HEALTH CRISIS

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CARE WORKFORCE

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

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ALZHEIMER'S & DEMENTIA CAREGIVERS

- 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)

22

[20]Alzheimer'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?

23

ALZHEIMER'S & DEMENTIA CAREGIVERS

- 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

24

[21]Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures.*

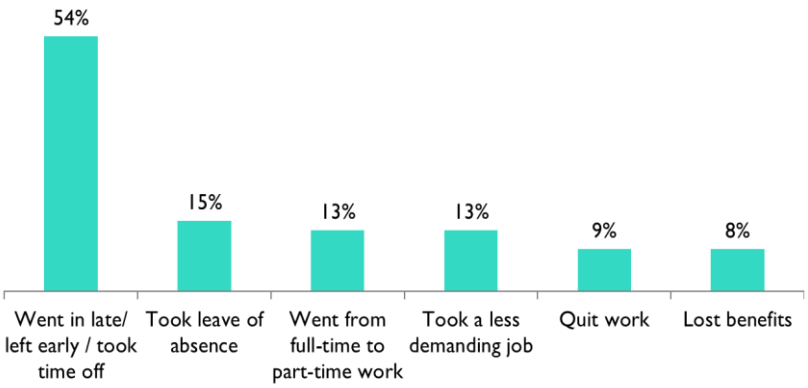
CAREGIVERS: CHALLENGES

- 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

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

25

CAREGIVERS: IMPACT ON WORK



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

26

CAREGIVERS: LENGTH OF CARE

- 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

[24]Alzheimer's Association. (2015) *Alzheimer's Disease Caregivers*.
[25]National Alliance for Caregiving & AARP (2009). *Caregiving in the U.S.*

27

CAREGIVERS: CRITICAL ROLE

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

28

HEALTH PROFESSIONALS: SHORTAGE

- 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

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

29

DIRECT CARE WORKFORCE

- 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

30

[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.*

DIRECT CARE WORKFORCE: CHALLENGES

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

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

31

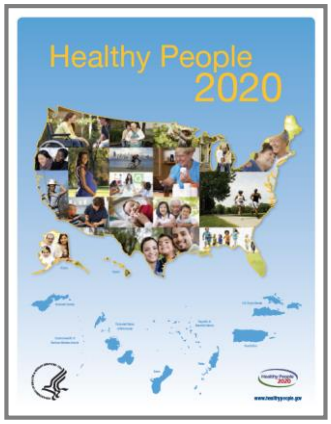
PUBLIC HEALTH APPROACH

ALZHEIMER'S DISEASE – A PUBLIC HEALTH CRISIS

32

HEALTHY PEOPLE 2020

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



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[30]Department 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

Public Health
Prevent. Promote. Protect.

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DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

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

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FOR MORE INFORMATION

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

alzheimer's association

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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

Selected Case Studies- Module 1

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 severally 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 martial 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=yJXTXN4xrI8
- **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 clips shows the difference in brain MRIs between the brains of an aging adult with no signs of Alzheimer's disease, an older adult with the brain pathology of Alzheimer's disease that is not yet cognitively impaired, and the brain of an older adult with progressive Alzheimer's disease. This clips also details the work of the Religious Orders Study that studies the progression of Alzheimer's disease as it affects the brain with a goal of how to age without memory loss, including the importance of a supportive social network.

k) "Searching for an Alzheimer's Cure: The Story of Flurizan"

- **Run Time:** 31:20 minutes
- **Key Terms:** drugs, treatment, Flurizan, non-steroidal anti-inflammatory drugs (NSAIDs), beta-amyloid 42, pharmaceutical industry, statistical significance, ethics
- **Description:** This clip discusses how current Alzheimer's medications only treat symptoms without changing the progression of the disease, but new drugs, specifically Flurizan, are being researched that aim to modify the progress of the disease by reducing the amount of amyloid plaque built up in the brain. This is currently the largest Alzheimer's drug trial which studies the drug's ability to effectively slow down the biological progression of Alzheimer's disease.

l) "The Pulse of Drug Development"

- **Run Time**: 15:55 minutes
- **Key Terms:** drugs, pathology, drug development, cleavage beta-amyloid plaque, detection, biomarkers, ethics, clinical trials, natural remedies, lifestyle changes
- **Description:** This clip discusses how advanced technology is improving the process to develop specific, early use treatment drugs for Alzheimer's disease.

m) "The DeMoe Family: Early-Onset Alzheimer's Genetics"

- **Run Time:** 25:43 minutes
- **Key Terms:** younger- (early) onset, genetics, family and intergenerational, predisposition, research, long term preparation, caregiver, family relationships, early diagnosis
- **Description:** This short documentary examines the DeMoe family which has the dominant gene for younger- (early) onset Alzheimer's disease. Doctors and researchers are studying the DeMoe family in order to learn more about this genetically inherited form of Alzheimer's disease.

n) "The Nanney/Felts Family: Late-Onset Alzheimer's Genetics"

- **Run Time:** 22:71 minutes
- **Key Terms:** late onset, research, genes, family, predisposition, early diagnosis, genetic mutation, gene sequencing, genetic background based risk, intergenerational
- **Description:** This short documentary studies the Nanney/Felts family that has the late onset form of Alzheimer's due to a genetic predisposition from a mutated gene that affects the beta-amyloid protein.

o) "The Quest for Biomarkers"

- **Run Time:** 17:06 minutes
- **Key Terms:** biomarkers, research, clinical trials, Pittsburgh Compound B (PIB) amyloid plaques, PET brain scanning, hereditary, spinal fluid, biofluids
- **Description:** This video details the search for biological indicators that can be used to identify individuals who are at a higher risk for developing Alzheimer's disease. Earlier detection of Alzheimer's disease could potentially lead to more effective Alzheimer's treatment and cures as well as allow for treatment prior to the occurrence of becoming symptomatic. The search for an indicative biological marker of Alzheimer's disease includes using brain imaging techniques and analysis of proteins in spinal fluid.

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

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

- **Modules:** 1, 3, 4

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

Programs Available for Purchase

(Listed in order of most recent production date)

1) "Still Alice," Sony Pictures Classics (2014).

- **Video Link:** http://sonyclassics.com/stillalice/
- **Run Time:** 101:00 minutes
- **Key Terms:** Alzheimer's disease, academia, family relationships, end of life planning, younger-onset
- **Purchase Price:**
  - Digital Download (Amazon): $12.99
  - DVD (Amazon): $12.59

Description:
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.theconnextion.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.