

A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS

MODULE 1:

ALZHEIMER'S DISEASE — A PUBLIC HEALTH CRISIS



alzheimer's 
association®



EMORY
ROLLINS
SCHOOL OF
PUBLIC
HEALTH

Emory Centers
for Training and
Technical Assistance

REVISED 2019

Table of Contents

About Module 1	3
Learning Objectives.....	3
Competencies	4
Layout of Module 1 Faculty Guide.....	5
How to Use the Materials	5
Student Engagement Options.....	6
Discussion Questions	6
Learning Activities.....	6
Additional Reading.....	7
Slide Guide	8
Sample Test Questions.....	50
Selected Case Studies-Module 1.....	51
Selected Video Resources-Module 1	56
Additional Learning Activities	63

ABOUT MODULE 1

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

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

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

Module 1 covers the following topics:

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

LEARNING OBJECTIVES

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

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

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

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

COMPETENCIES

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

Academy for Gerontology in Higher Education (AGHE):

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

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

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

Council on Linkages Between Academia and Public Health Practice:

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

Disclaimer:

The mark "CDC" is owned by the US Department of Health and Human Services and is used with permission. Use of this logo is not an endorsement by HHS or CDC of any particular product, service, or enterprise.

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: <https://www.hhs.gov/web/section-508/making-files-accessible/index.html>)

STUDENT ENGAGEMENT OPTIONS

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

DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

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

LEARNING ACTIVITIES

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

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

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

ADDITIONAL READING

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

SLIDE GUIDE

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

SLIDE 1:

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

TALKING POINTS:

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

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

SLIDE 2:

Learning Objectives

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

TALKING POINTS:

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

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

SLIDE 3:

Alzheimer's – Public Health Crisis¹

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

TALKING POINTS:

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

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

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

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

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

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

Image source: Pixabay.com

SLIDE 4:

What is Dementia?^{2,3}

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

TALKING POINTS:

It is first important to understand what characterizes dementia.

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

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

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

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

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

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

SLIDE 5:

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

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

TALKING POINTS:

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

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

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

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

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

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

Image source: National Institute on Aging

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

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

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

Link: https://www.alz.org/alzheimers-dementia/what-is-alzheimers/brain_tour

SLIDE 6:

SCOPE OF THE EPIDEMIC

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

SLIDE 7:

Scope of the Epidemic (U.S.)⁶

- Over 5.8 million adults
- 1 in 10 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 5.8 million adults** in the U.S. are living with Alzheimer's disease, including an estimated 200,000 under the age of 65.

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

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

⁶ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

Image source: Pexels.com

SLIDE 8:

Health Disparities^{7,8}

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

TALKING POINTS:

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

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

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

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

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

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

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

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

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

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

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

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

SLIDE 9:

Alzheimer's Deaths⁹

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

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

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

⁹ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

SLIDE 10:

Changes in Causes of Death (2000-2017) (*bar chart*)¹⁰

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

TALKING POINTS:

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

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

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

¹⁰ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

SLIDE 11:

Growing Epidemic^{11,12}

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

TALKING POINTS:

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

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

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

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

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

¹¹ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

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

Image source: Pexels.com

SLIDE 12:

Worldwide Epidemic¹³

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

TALKING POINTS:

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

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

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

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

SLIDE 13:

FINANCIAL BURDEN

TALKING POINTS:

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

SLIDE 14:

Financial Burden: U.S. & Worldwide^{14,15}

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

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

¹⁴ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

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

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

SLIDE 15:

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 16:

Medicare & Medicaid¹⁶

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

TALKING POINTS:

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

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

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

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

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

Image source: Pexels.com

SLIDE 17:

Alzheimer's: Medicare & Medicaid^{17,18}

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

TALKING POINTS:

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

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

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

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

¹⁷ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

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

SLIDE 18:

Alzheimer's: Projected Costs (2050)^{19,20}

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

TALKING POINTS:

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

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

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

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

¹⁹ Alzheimer's Association. (2016) *2016 Alzheimer's Disease Facts and Figures*.

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

Image source: Pexels.com

SLIDE 19:

CARE BURDEN

TALKING POINTS:

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

SLIDE 20:

Care Workforce

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

TALKING POINTS:

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

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

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

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

SLIDE 21:

Alzheimer's & Dementia Caregivers²¹

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

TALKING POINTS:

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

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

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

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

²¹ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

SLIDE 22:

Discussion Question

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

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

Open responses.

SLIDE 23:

Alzheimer's & Dementia Caregivers^{22,23}

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

TALKING POINTS:

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

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

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

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

²² Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

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

Image source: Pixabay.com

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

- Medication management, financial management
- Providing emotional support

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

SLIDE 24:

Caregivers: Challenges²⁴

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

TALKING POINTS:

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

Several recent findings highlight these challenges:

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

²⁴ Alzheimer's Association. (2018) *Alzheimer's Disease Caregivers*.

Image source: Pexels.com

SLIDE 25:

Caregivers: Impact on Work²⁵

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

TALKING POINTS:

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

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

- 57% said they had to go in late, leave early, or take time off because of their caregiving responsibilities
- 18% had to go from working full time to part time
- 16% took a leave of absence
- 8% turned down a promotion
- 1 in 6 had to quit work entirely either to become a caregiver or because their caregiving duties became too demanding.

²⁵ Alzheimer's Association. (2018) *Alzheimer's Disease Caregivers*.

SLIDE 26:

Caregivers: Length of Care^{26,27}

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

TALKING POINTS:

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

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

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

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

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

²⁶ Alzheimer's Association. (2018) *Alzheimer's Disease Caregivers*.

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

Image source: Pexels.com

SLIDE 27:

Caregivers: Critical Role

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

TALKING POINTS:

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

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

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

Image source: Pexels.com

Image source: Pexels.com

SLIDE 28:

Health Professionals: Shortage^{28,29}

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

TALKING POINTS:

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

Current estimations of workforce shortages include:

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

²⁸ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

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

SLIDE 29:

Direct Care Workforce³⁰

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

TALKING POINTS:

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

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

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

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

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

³⁰ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

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

SLIDE 30:

Direct Care Workforce: Challenges³¹

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

TALKING POINTS:

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

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

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

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

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

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

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

SLIDE 31:

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 32:

Healthy People 2030³²

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

TALKING POINTS:

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

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

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

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

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

Image source: Pexels.com

SLIDE 33:

Role of Public Health³³

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

TALKING POINTS: (See module 3 for more information)

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

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

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

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

Image source: Unsplash.com

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

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

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

SLIDE 34:

Dementia Capable Systems and Dementia Friendly Communities

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

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

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

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

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

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

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

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

SLIDE 35:

For More Information

For more information, please visit:

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

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

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

TALKING POINTS:

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

SLIDE 36:

Competencies

Academy for Gerontology in Higher Education (AGHE):

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

Council on Education for Public Health (CEPH)

Foundational Competencies

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

Council on Linkages Between Academia and Public Health Practice:

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

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

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

Academy for Gerontology in Higher Education (AGHE):

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

Council on Education for Public Health Foundational Competencies

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

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

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

Council on Linkages Between Academia and Public Health

Practice:

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

SAMPLE TEST QUESTIONS

1- What is dementia?

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

Answer: B

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

- a. True
- b. False

Answer: A

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

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

Answer: C

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

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

Answer: C

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

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

Answer: A

Selected Case Studies- Module 1

Based on faculty requests, a set of case studies have been developed for use with one or more of the curriculum modules. The case studies can be used in class or as an outside assignment.

The case studies are designed to be used in conjunction with the article or video listed. All case study videos come from the curriculum's video resource list, and there are several well done documentaries that cover various aspects of Alzheimer's and its impacts on individuals and families. For video-based case studies, the program title, run time, web link, keywords, relevance to modules, a program description and discussion questions are listed for each piece. However, if time and/or internet access is limited, each case study has a summary that provides enough information to generate discussion or conversation without needing to access the video/audio.

1. "Alzheimer's Disease Underdiagnosed in Indian Country," NPR (2015).

- **Audio/Transcript Link:**
<http://www.npr.org/templates/transcript/transcript.php?storyId=458041798>
- **Run Time:** 3:46 minutes (audio)
- **Key Terms:** cultural context, Native Americans, diagnosis, community outreach, family relationships, tradition, stigma, caregiver burden, long term care
- **Modules:** 1, 3, 4

Description:

Mrs. Williams is an older woman who has been having severe memory problems for the past seven years. Mrs. Williams lived on a Native American reservation in Arizona before moving in with her daughter, Delma, in Los Angeles. In many tribal communities, obtaining an Alzheimer's diagnosis is a challenge; for example, tribal communities may not have a word for dementia. Native American cultures have historically considered aging and signs of Alzheimer's (memory issues, forgetfulness, getting lost) as part of the cycle of life: people begin life as children and leave as children. Mrs. Williams' daughter did not know what Alzheimer's disease is because no one ever talked about it.

Once in Los Angeles, Mrs. Williams' memory problems grew increasingly worse. Mrs. Williams began wandering and becoming lost. During moments of lucidity, Mrs. Williams begged her daughter to return her to her home on the reservation. Eventually Delma and her family moved back to the reservation. Mrs. Williams has 13 other children who live in that area, but Delma is the only one who cares for their mother. Delma is not sure why her siblings do not visit their mother

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

and their absence upsets her. Delma also feels guilty for doubting her mother when she first mentioned having memory issues.

Discussion Questions:

- Why is cultural humility and respect important in public health?
- In this story, what are cultural barriers to diagnosing and understanding Alzheimer's disease?
- How can public health address Alzheimer's disease misinformation and stigma in a culturally competent and relevant way?
- What is the role of family and care in an Alzheimer's disease diagnosis?
- What components may be useful in creating a community outreach program for this particular community?

2. "When Mom Has Alzheimer's: A Stranger Comes for Christmas," NPR (2015).

- **Audio/Transcript Link:**
<http://www.npr.org/templates/transcript/transcript.php?storyId=460042950>
- **Run Time:** 2:44 minutes (audio)
- **Key Terms:** caregiver burden, family, long term care, social stigma
- **Modules:** 1, 3, 4

Description:

Helen was diagnosed with Alzheimer's disease seven years ago and now lives with her son, Terry, and his wife, Mary. Terry and Mary have created a structured routine for Helen that involves time at the adult day center that provides socialization with other older adults, engaging activities, and care. This routine has become an important part of maintaining Helen's health and wellness.

The winter holidays are coming up, and Terry and Mary must strategize about how to celebrate with family and friends without disrupting Helen's routine. The winter holidays are additionally stressful to families caring for members with Alzheimer's and can make caretakers feel overwhelmed. Terry and Mary must prepare visiting relatives for Helen's worsening condition. They also must mentally prepare themselves for the disappointment of fewer and fewer friends visiting to celebrate the holidays. Terry and Mary are exhausted all the time and say that they are just trying to get through Christmas now.

As Helen's Alzheimer's progresses, Terry and Mary have come to accept that their lives are very different than from seven years ago when Helen moved in, and they continue to make personal sacrifices in order to take the best possible care of Helen. For example, Terry and Mary can no longer go to all of their friends' and family's various holiday celebrations anymore, and often friends and family don't understand why. Terry and Mary have accepted they can no longer do everything

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

they once did during the holidays; however, they still feel the sense of missing out and being excluded.

Discussion Questions:

- What are ways that extended family and friends could be more inclusive and understanding of this couple's difficult situation?
- How can public health reduce social stigma surrounding Alzheimer's disease?
- What kinds of basic information about Alzheimer's should most people know?
- What kind of modifications can be made in the home to increase safety and independence for the individual with Alzheimer's disease?

3. "Inside Alzheimer's: What's It Like to Live with Early-Onset Alzheimer's Disease? Greg O'Brien Offers a Glimpse," NPR special series (2015).

- **Audio/Transcript Link:** <http://www.npr.org/series/389781574/inside-alzheimers>
- **Run Time:** 4-6 minutes per segment (audio)
- **Key Terms:** progression, younger-(early) onset, cancer, long term care, end of life decisions, caregiver burden, spouse/partner relationship, family relationship, loss of appetite, loss of smell, loss of taste, hallucinations, medications, GPS app, loss of identity
- **Modules:** 1, 2, 4

Description:

A nine part series of articles and audio clips that chronicle aspects of one man's journey with Alzheimer's disease; audio clips are 4-6 minutes each.

Writer Greg O'Brien was diagnosed with younger-onset Alzheimer's disease six years ago when he was 59 years old. Not only was he diagnosed with younger-onset Alzheimer's, but he was also diagnosed with stage-three prostate cancer a few years later. Greg is a journalist and writer living in Cape Cod with his wife, Mary Catherine, and their three children. Greg began demonstrating signs of Alzheimer's dementia, such as memory loss and getting lost, as his own mother was in the end stages of Alzheimer's.

Mary Catherine says that Alzheimer's changed Greg's personality in many ways. On one hand, Greg discusses certain topics with her more openly than he would have in the past, but she also has noticed that he gets angry now, something he never used to do before. In the past, Greg was a loud, outgoing man who was often at the center of discussion. Now he is quieter and more solitary, even disappearing into a different room when crowds of visitors become overwhelming for him. Greg also used to run upwards of six miles daily as a part of his daily routine; however, he began getting lost and switched to running in a gym.

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

Greg's personality is not the only thing that has changed since his younger-onset Alzheimer's diagnosis. Greg's appetite and sense of taste and smell have declined. Greg says that food now often tastes the same, like "rolled up newspaper." Greg does buy frozen fruit bars and states that although they have no taste, they do feel cold, which is a different and enjoyable sensation.

As Greg's Alzheimer's has progressed over the past six years, so have his hallucinations. Hallucinations are a rarely discussed aspect of Alzheimer's but can often accompany memory loss. According to Greg's doctors, these hallucinations are due to the changes in his brain as a result of the disease.

Mary Catherine's and Greg's outlook on life has also changed over time. For example, Mary Catherine says that she no longer can get impatient, which is difficult, but important. In the beginning of his diagnosis, Greg used to get very angry, but now he no longer does as he tries to focus on the moment instead of the past or future. Mary Catherine believes their marriage has gotten even stronger.

Because of Greg's Alzheimer's, Greg and Mary Catherine have had to make many difficult decisions, including deciding to sell their house that Greg built, where they raised their three children and planned to grow old together. Growing old in that house together is no longer a realistic possibility.

Greg, Mary Catherine, and his physician have discussed "exit strategies" for Greg while he is still aware and able to make these types of decisions. One of these exit strategies includes not treating his stage three prostate cancer. Greg's physician says that not treating the prostate cancer will most likely shorten his life, but Greg is okay with this because he would rather his life be shortened by the prostate cancer than by Alzheimer's. Greg states that he is most afraid of the "in-between." He loves living and he is not afraid to die, but he fears the middle portion, the loss of identity and independence, and dreads his family's suffering as they watch his slow decline.

Discussion Questions:

- Why is it important that individuals with Alzheimer's disease are diagnosed early?
- In what ways can Greg maintain his independence as his Alzheimer's progresses?
- Discuss the importance of end of life planning and role of public health in encouraging people to make plans.
- Discuss the importance of a strong social network and family support.
- Discuss the advantages and disadvantages of deciding not to treat stage-three prostate cancer as Alzheimer's progresses.

4. “Following a Couple from Diagnosis to the Final Stages of Alzheimer’s,” CBS News (2018).

- **Video Link:**
https://www.cbs.com/shows/60_minutes/video/NdL7R_Ds72aHh9tZg8nacFW_5ZB4wMC/following-a-couple-from-diagnosis-to-the-final-stages-of-alzheimer-s/
- **Run Time:** 13:18 minutes
- **Key Terms:** caregiver’s burden, family relationships, financial burden, end of life planning
- **Module:** 1, 2

Description:

This 60 Minutes segment follows Dr. Jon LaPook’s who has been checking in on Carol Daly, a woman diagnosed with Alzheimer's, and her caregiver husband, Mike, each year for the last 10 years to see how the disease progresses. The segment illustrates the devastating impact the disease has on both of them over the decade.

Discussion Questions:

- Describe some of the physiological changes that occur for Carol over the course of the video.
- In what ways is Mike impacted by the disease?
- What are some of the challenges, changes, and tough decisions Mike and Carol experienced?

Selected Video Resources- Module 1

The following videos are listed as suggested accompaniments to the curriculum modules. These could be shown in class or as suggested viewing outside of class. Please note that some of the videos listed are only for purchase. Check with your specific institution to see if some videos may be available through your universities' library resources for free.

1. "6 Siblings Living in the Shadow of Alzheimer's," TODAY Show (2017).

- **Video Link:** <https://www.youtube.com/watch?v=dLiu07V4cUI>
- **Run Time:** 6:20 minutes
- **Keywords:** early onset, caregiver, genetic
- **Modules:** 1, 2, 3

Description:

The DeMoe family are fighting a unique battle against Alzheimer's disease. Five of the six DeMoe siblings have tested positive for early onset Alzheimer's disease. Their father was diagnosed with Alzheimer's in his 40s. They share their story and how their own children have been impacted by the disease.

2. "14 Days with Alzheimer's: A Film By Lisa Cerasoli," Lisa Cerasoli (2012).

- **Video Link:** http://www.amazon.com/14-Days-Alzheimers-Film-Cerasoli/dp/1589850998/ref=sr_1_1?s=movies-tv&ie=UTF8&qid=1427304005&sr=1-1&keywords=14+days+with+alzheimer%27s
- **Run Time:** 29:00 minutes
- **Keywords:** caregiver burden, family relationship
- **Modules:** 1, 2, 3
- **Purchase Price:** \$18.22*

Description:

Winner of the Audience Choice Award at the Life and Death Matters Film Festival, Boulder, Colorado. Based on the memoir, *As Nora Jo Fades Away*, this short documentary examines 14 days in the life of the filmmaker's grandmother.

3. "Alzheimer's: An Emerging Public Health Issue," Alzheimer's Association (2017).

- **Video Link:** <https://www.youtube.com/watch?v=f0a8KuYlpy4&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU&index=12&t=0s>
- **Run Time:** 9:30 minutes
- **Key Terms:** public health, prevention, intervention

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

- **Modules:** 1, 3

Description:

Historically, Alzheimer's disease has been seen as an aging issue, but more and more people are viewing Alzheimer's as a public health issue because the burden is large, the impact is major, and there are ways public health can intervene. This video provides an overview of Alzheimer's disease as a public health issue and the ways that public health professionals can intervene.

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

- **Video Link:** <https://www.youtube.com/watch?v=vR-cwADz-V0>
- **Run Time:** 1:20 minutes
- **Key Terms:** public health, data
- **Modules:** 1

Description:

Brief overview of the Alzheimer's Association's 2019 facts and figures on Alzheimer's disease that covers prevalence and impact figures.

5. "Communicating with People with Dementia: New Educational Videos," Alzheimer's Association (2017).

- **Video Link:** See individual episode links below
- **Key Terms:** dementia, selfhood, communication, caregivers
- **Modules:** 1, 4

Description:

This new educational resource can help the public and professionals communicate effectively and sensitively with people with dementia. In a series of three videos – *Communicating with People with Dementia: Understanding Their Selfhood*, Dr. Steven Sabat of Georgetown University speaks about the importance of language in communications with persons with Alzheimer's and other dementias. He describes how the words we choose can lessen the social stigmas associated with dementia. Stories illustrate different communications choices with regards to the selfhood of people with dementia.

A. "The Effects of Labeling Relationships (part 1)"

- **Video Link:** <https://www.youtube.com/watch?v=kPppik-FtGE&index=13&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU&t=49s>
- **Run Time:** 15:52 minutes
- **Key Terms:** stigma, selfhood, communication, caregivers
- **Module:** 1, 4

Description:

Dr. Steven Sabat of Georgetown University speaks about the importance of language when communicating with individuals who have been diagnosed with Alzheimer's disease and other dementias. In this video, Dr. Sabat explains how labels (such as doctor-patient) can affect the nature of the relationship and the importance of personal attributes.

B. "The Value of Individuality (part 2)"

- **Video Link:**

- <https://www.youtube.com/watch?v=7MC2dctNTzE&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU&index=13>

- **Run Time:** 12:40 minutes

- **Key Terms:** dementia, selfhood, communication, caregivers

- **Module:** 1, 4

Description: Dr. Sabat speaks about the effects of the label "patient." Dr. Sabat offers advice on how to communicate with and describe individuals living with Alzheimer's disease and other dementias to better emphasize their individuality.

C. "Normal Behaviors Post-Diagnosis (part 3)"

- **Video Link:** <https://www.youtube.com/watch?v=t27Z-IfCRzU&index=14&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU>

- **Run Time:** 16:17 minutes

- **Key Terms:** dementia, selfhood, communication, caregivers

- **Module:** 1, 4

Description:

In this video, Dr. Sabat discusses a case study that illustrates how normal behaviors are perceived differently after receiving an Alzheimer's or other dementia diagnosis and how important it is to remember to treat these behaviors as normal.

10. "A Different Visit: Montessori-Based Activities for People with Alzheimer's/Dementia," Center for Applied Research in Dementia (2012).

- **Video Link:** <https://www.youtube.com/watch?v=FLDwzgRTbVA>

- **Run Time:** 8:07 minutes

- **Key Terms:** caregivers, emotional health, meaningful visits

- **Modules:** 1, 2, 3, 4

Description:

This clip gives suggestions about how to have a meaningful visit with someone who has been diagnosed with Alzheimer's disease. The video emphasizes focusing on

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

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).

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

- **Video Link:** <https://www.youtube.com/watch?v=ecp7lgQS1v0&index=23&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU>
- **Run Time:** 1:01:52 minutes
- **Key Terms:** caregiver, BRFSS, surveillance, public health, Healthy Brain Initiative Road Map
- **Module:** 1, 2, 3

Description:

Webinar presented by the Alzheimer's Association discussing overview of 2016 BRFSS Caregiver Module in New York, and the origin and first year results of the Alzheimer's Disease Caregiver Support Initiative (ADCSI) in New York. Featured speakers include Dr. Erin Bouldin, Dr. David Hoffman, and Dr. Mary Gallant.

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

- **Video Link:** https://www.amazon.com/First-Cousin-Once-Removed-Berliner/dp/B00J7JXMBE/ref=sr_1_1?keywords=first+cousin+once+removed&qid=1547758337&sr=8-1
- **Run Time:** 27:00 minutes
- **Key Terms:** progression, caregiver, intervention
- **Modules:** 1, 2, 3, 4
- **Purchase Price:** Amazon
 - Buy \$11.99
 - Rent 3.99

Description:

Edwin Honig is a distinguished poet, translator, critic, teacher, honorary knight, and cousin and mentor to the filmmaker, Alan Berliner. Shot over five years for HBO, First Cousin Once Removed documents Honig's experience with Alzheimer's through conversations with family and friends. Berliner captures Honig's literary skills, playfulness and poetic soul, obvious even through his cognitive impairment.

13. “Following a Couple from Diagnosis to the Final Stages of Alzheimer’s,” CBS News (2018).

- **Video Link:** https://www.cbs.com/shows/60_minutes/video/NdL7R_Ds72aHh9tZg8nacFW_5ZB4wMC/following-a-couple-from-diagnosis-to-the-final-stages-of-alzheimer-s/
- **Run Time:** 13:18 minutes
- **Key Terms:** caregiver’s burden, family relationships, financial burden, end of life planning
- **Modules:** 1, 2, 3, 4

Description:

This 60 Minutes segment follows Dr. Jon LaPook’s who has been checking in on Carol Daly, a woman diagnosed with Alzheimer's, and her caregiver husband, Mike, each year for the last 10 years to see how the disease progresses. The segment illustrates the devastating impact the disease has on both of them over the decade.

14. “GAPS,” Peter Trinh (2018).

- **Video Link:** <https://vimeo.com/268811803/6745380c62>
- **Run Time:** 15:24 minutes
- **Key Terms:** stigma, Asian culture, community, awareness
- **Modules:** 1, 4

Description:

This documentary examines the cultural and epidemiological aspects of Alzheimer’s disease and other dementias among Asian American/Pacific Islanders (AAPI). Although dementias and related neurodegenerative diseases are major public health issues around the world, cultural stigmas and traditions play a role in how they are dealt with in Asian communities. This may be particularly true of Alzheimer’s disease. Alzheimer's disease affects millions of Asians, yet in most Asian countries and cultures, a word does not exist to describe the disease. Trang Tu shares her emotional stories of being the full-time caregiver to her mom, who is living with Alzheimer’s. Trang has experienced the difficulties and pressures of caring for her mother as an Asian-American and dealt with a system that has not yet fully understood or addressed the need for culturally relevant resources. These same topics are also discussed in the documentary with professional health care experts from various organizations and universities, including the Alzheimer’s Association, University of Washington, and the University of California, San Francisco.

15. “Grandpa, Do you know who I am?” The Alzheimer’s Project on HBO (2016).

- **Video Link:** <https://www.hbo.com/documentaries/the-alzheimers-project-grandpa-do-you-know-who-i-am>

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

- **Run Time:** 30:48 minutes
- **Key Terms:** children, family, impact of disease on family
- **Modules:** 1, 4
- **Purchase Price:** HBO subscription required

Description:

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

16. "Healthy Aging: Promoting Well-being in Older Adults," CDC (2017).

- **Video Link:** <https://www.cdc.gov/grand-rounds/pp/2017/20170919-senior-aging.html>
- **Run Time:** 1:05:04 minutes
- **Key Terms:** prevention, health behaviors, intervention, aging, workforce, chronic disease
- **Modules:** 1, 2, 3, 4

Description:

CDC's Public Health Grand Rounds in September 2017 focuses on aging, chronic disease (including Alzheimer's disease), role of caregivers, and the role of public health.

17. "Still Here," Wake Forrest (2018).

- **Video Link:** <https://vimeo.com/279478897/788d394e8f>
- **Run Time:** 35:05 minutes
- **Key Terms:** American Indian communities, community, care taking
- **Modules:** 1, 2, 3, 4

Description:

This documentary examines caregiving and the impact of Alzheimer's disease and other dementias in American Indian communities. The film focuses on American Indian families and tribal communities in North Carolina.

18. Teepa Snow (2018).

- **Video Links:** <https://teepasnow.com/resources/about-dementia/>
- **Run Time:** 2- 6 minutes each
- **Key Terms:** dementia, caregivers, activities, behavior
- **Module:** 1, 2, 4

Description:

Teepa Snow is an occupational therapist with 40 years of clinical practice experience. In 2005, she founded Positive Approach to Care (PAC) to provide dementia care training, services, and products to professionals and family caregivers to change the culture of dementia care and increase awareness. Videos include the following topics:

- **Activities:** Reviews four categories of activity that help individuals feel valued, productive, and purposeful. The categories are work, leisure, self-care, and rest and restoration.
- **Behaviors:** Discusses the ways providers can approach behavior change among individuals with dementia, in a productive and respectful manner.
- **Brain change:** A brief overview of how the brain is changed due to dementia.
- **Dementia 101:** Overview of early signs of dementia and what is and is not normal aspects of aging.
- **Teepa's GEMS®:** Teepa's model builds upon existing progression models that define changes in an individual due to dementia and focuses on ability, rather than skills lost.
- **Music:** Reviews the benefits of music therapy for individuals with dementia and providers.

19. "Your Fantastic Mind," Georgia Public Broadcasting (2019).

- **Video Link:** <http://www.gpb.org/television/shows/your-fantastic-mind/episode/893dced9-2604-4029-a41d-c7fbb0f2f22d>
- **Run Time:** 11:50 (stop video at 11:50 minutes)
- **Key Terms:** early onset, caregiver, prevention, risk reduction, Alzheimer's research
- **Modules:** 1, 2, 3

Description:

Cecile Bazaz was a high-level banking executive in her 40s when she was diagnosed with Alzheimer's disease at 49 years old. This video discusses early onset Alzheimer's disease and who it impacts. Leading researchers also discuss how you can lower your risk of developing Alzheimer's disease.

Additional Learning Activities

The following suggestions are additional learning activities that can be used to increase student interaction and engagement with the, *A Public Health Approach to Alzheimer's and Other Dementias* curriculum.

Reverse Classroom Approach

The reverse classroom, also known as the flipped classroom, is an approach that provides students with instructional materials to review outside of the classroom and encourages assignments that mirror homework to be used during the designated instructional time. Examples of incorporating this approach are as follows:

- **Think, Pair, and Share.** Assign students to review the curriculum, video, case study, or related assignment and propose a question about the material at the start of the next class. Students will first think quietly for a minute or two to collect their thoughts and questions about the material. Next, students will pair up and discuss their thoughts with a partner or small group. Finally, each pair will briefly share their discussion with the class. This activity can be used at the start of class to help students review any assignments. Alternatively, this activity can also be used at the end of class to help students reflect on the day's teachings.
- **Mini Curriculum.** Divide the class into four groups and have each group present one module to the class. Ask students to create a "mini curriculum" to teach their peers about Alzheimer's disease and the role public health and related disciplines plays. This assignment is meant to be creative and allows students to use any platform they think would work best for their peers to learn the material by using video, lecture, handout, games, or discussion. This may also provide insight into your students' preferred learning style.
- **Reflection Paper.** Reflection papers allow students not only to reflect on the curriculum, but also on the larger effect Alzheimer's and other dementias have on society. Students will review a module, case study, or video as assigned and then write a reflection paper that will be used to guide discussion during the next class. These reflections should ask students to critically think about the topic at hand, but do not need to be a specific length. This activity may also be done during class time by setting a 5-minute timer and asking students to write down their reflections from the class that day.

Learning Lab

A learning lab instructional approach is participatory and results-oriented with the sole objective of students working together to innovatively solve an issue or public health challenge. In each activity, students are tasked with thinking through various potential actions to solve the challenges raised using a public health lens.

Examples of incorporating this approach are as follows:

- **Assistive Technology.** Break the class into groups and ask them to come up with an innovative assistive technology or monitoring system to support individuals living with dementia and their caregivers. This is meant to be a creative project and students do not have to produce an actual product; however, students should demonstrate their knowledge of the behavioral and physical changes associated with Alzheimer's and other dementias.
- **Policy Brief.** Ask students to write a one-page policy brief and present it to the class. Using what they have learned from the curriculum, videos, and case studies, students should be able to identify a need of someone living with dementia or their caregiver that can affect policy change. The policy brief should include the following sections: title, summary, scope of problem, policy alternatives, policy recommendations, and sources. Students should also have a specific audience in mind for the policy brief, such as a Member of Congress. This activity can be done by an individual or group.
- **What's Happening in the News?** Ask students to find a recent scholarly article or news article related to Alzheimer's. Students may find articles related to prevention, clinical trials, interventions, or other related topics and be prepared to briefly explain them to the class. The purpose of this activity is to expose students to the current state of Alzheimer's research and to learn more about public health and related disciplines in action. Helpful resources may include the National Institutes of Health, Centers for Disease Control and Prevention, Alzheimer's Association, credible newspapers, scholarly articles, and research happening at your own university.
- **Case Study Stations:** This activity allows students to get up and move around the class as they visit different case studies placed around the room. It is suggested that you use the My Typical Day case studies (available at <http://www.mytypicalday.org/>) for this activity, but feel free to use any examples from the provided case studies in the curriculum. Print a copy of each case study you have selected (as many as appropriate for your class size) and place them around the classroom. Students will then break into small groups and rotate around the room to read and discuss each case study. Students should discuss each case both from the perspective of the individual, but also the caregiver and others involved if applicable. Prompts for the students are listed below.
 - In what ways has life changed since their diagnosis?

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

- How have they reacted to their diagnosis? Positively? Negatively?
- How have they adapted their everyday routine?
- What support do they have?
- What changes have they noticed?
- What role do their family and friends play?
- **Dementia Friendly Communities.** The sources below provide visual images and key takeaways on how communities can be dementia friendly. After reviewing the example images as a class, students will be asked to draw their own community and identify ways in which their community is dementia friendly and ways their community could improve. Students may choose the town or city where the university is located or even their own hometown if they would like to offer a different example to the class. If you would like to make this a group activity, project a map of your university on a chalkboard or whiteboard and have students draw directly on it during class time.
 - Fostering Dementia Friendliness: <https://www.dfamerica.org/communities-overview>
 - Building Dementia –Friendly Communities: A Priority for Everyone: <https://dementiapartnerships.com/resource/building-dementia-friendly-communities/>
 - Dementia Friendly Community Toolkit: <https://www.actonalz.org/dementia-friendly-toolkit>

Guest Speakers

Pairing the curriculum with guest speakers is an instructional approach that allows students to learn from the experiences of people who have been affected by Alzheimer's and other dementias or work in a related field.

Examples of guest speakers include:

- Caregivers of someone with dementia.
- An individual with early stage dementia.
- Local Alzheimer's Association chapter.
- Nonprofit organization working on issues related to dementia.
- A local department of public health, another government agency, or a community-based group such as an Area Agency on Aging.
- Nurses, doctors, social workers, and other professionals who work with individuals with dementia.
- Faculty and staff at your university who are conducting related research.

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

Test Your Knowledge

Quiz the class using the Alzheimer's Disease Knowledge Scale (ADKS). The ADKS contains 30 true or false items to assess their knowledge about Alzheimer's disease. The scale addresses topics such as risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, treatment, and management. This is a quick way to gauge what the students have learned, without creating a formal exam. Students can take the quiz independently (5 to 10 minutes) and then review the answers as a class. The ADKS and answers to each question can be found at the Resources for the Alzheimer's Disease Knowledge Scale website using this link: <https://pages.wustl.edu/geropsychology/adks>