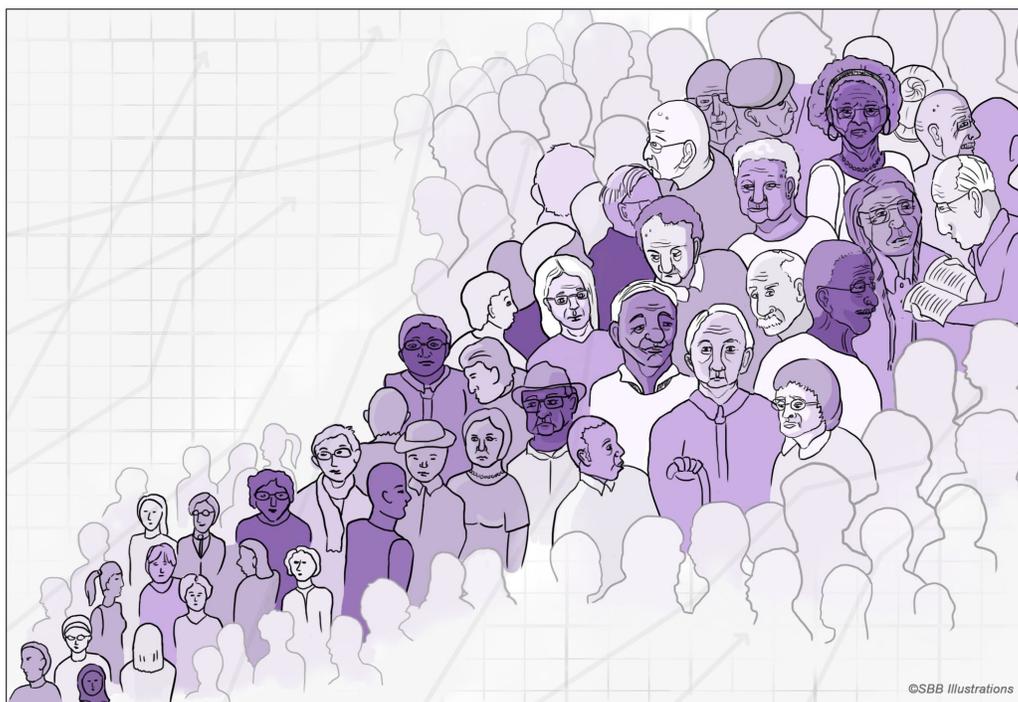


# A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS

## MODULE 4:

### DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES



alzheimer's   
association®



EMORY  
ROLLINS  
SCHOOL OF  
PUBLIC  
HEALTH

Emory Centers  
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Technical Assistance

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### ABOUT MODULE 4

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

**Module 4: Dementia Capable Systems and Dementia Friendly Communities** addresses the public health response to the Alzheimer’s disease epidemic at the state and community levels. The module describes the concepts of “dementia capable” systems and dementia friendly communities, both of which involve accommodating the needs of a population with memory loss, and a variety of related **physical, cognitive, and behavior** symptoms, as well as other **co-morbidities**.

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

#### **Module 4 contains the following topics:**

1. Community-support needs assessments
2. Support services & programs
3. Workforce training
4. Dementia friendly communities

### LEARNING OBJECTIVES

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

- Define dementia capable systems and dementia friendly communities
- Explain how public health can contribute to the development of dementia capable systems by analyzing community-support needs, developing support services and programs, establishing workforce training, and the creation of dementia friendly communities.
- List at least two support services that may benefit a caregiver of someone with Alzheimer’s or dementia
- Identify at least three professions that would benefit from workforce training related to Alzheimer’s and dementia

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

- Describe at least two components of a dementia friendly community

### COMPETENCIES

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

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

- 1.6.7 Promote and apply the use of appropriate forms of evidence-based interventions and technologies for older adults, their families, and caregivers
- II.4.5 Provide information and education to the following groups in order to build a collaborative aging network:
  - Key persons in the community (police officers, firefighters, mail carriers, locale service providers, and others)
  - Aging workforce professionals and personnel (paid and unpaid; full-and part-time) in the field of aging

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

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

#### **Council on Linkages Between Academia and Public Health Practice:**

- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence, and innovation)

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## LAYOUT OF MODULE 4 FACULTY GUIDE

This guide is laid out in the following sections:

- Slide guide with talking points
- Sample test questions
- Case studies
- Video resources

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

### HOW TO USE THE MATERIALS

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

### STUDENT ENGAGEMENT OPTIONS

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

### DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

- Imagine you or someone you care about has Alzheimer's or dementia. What might be some of your concerns or fears about going out in your community? How could those be addressed at a community level? *(Slide 5)*
- What kinds of support services might people with Alzheimer's and their caregivers need? *(Slide 12)*
- What is the role of public health in connecting people to the services they need? *(Slide 15)*
- What training should health care and direct care professionals receive? *(Slide 20)*
- What training should public health professionals receive? *(Slide 22)*
- What training should first responders receive? *(Slide 24)*

### LEARNING ACTIVITIES

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

- Conduct a brief observational study of the community in which you live, work, or go to school. What characteristics could be considered dementia friendly? What changes would be needed? How could public health support the development or growth of a dementia friendly community where you live/work/study?
- Select a workforce (such as public health, health care, first responder, etc.) that would benefit from training on Alzheimer's and dementia. Create an outline of training topics- what information would you present? What educational techniques would you use during the training?
- View the following videos from two different cultures: Asian-American and American Indian. Compare and contrast how these communities address Alzheimer's and dementia.

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

- Asian American: <https://vimeo.com/268811803/6745380c62>
- American Indian: <https://vimeo.com/279478897/788d394e8f>

### ADDITIONAL READING

- Alzheimer's Association. (2019). Alzheimer's Disease Facts and Figures. Chicago, IL: Alzheimer's Association. <http://www.alz.org/facts>
- Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018. <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
- Bynum, J. (2014). The long reach of Alzheimer's disease: Patients, practice, and policy. *Health Affairs*, 33(4), 534-540. Retrieved from <http://content.healthaffairs.org/content/33/4/534.short>
- Hoffman, D. (2015, July 14). Looking at the future of Alzheimer's disease policy. [Blog post]. Retrieved from <https://www.healthaffairs.org/doi/10.1377/hblog20150714.049333/full/>
- Lin, S. Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future. *The Gerontologist*, 55(2), 237-244. <http://gerontologist.oxfordjournals.org/content/55/2/237.short>

## SLIDE GUIDE

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

### SLIDE 1:

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#### Module 4: Dementia Capable Systems and Dementia Friendly Communities

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#### TALKING POINTS:

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

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

## SLIDE 2:

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### Learning Objectives

- Define dementia capable system and dementia friendly community
- Explain how public health can contribute to dementia capable systems through support services/programs, workforce training, and dementia friendly communities
- List at least two services that may benefit a caregiver
- Identify at least three professions that would benefit from workforce training
- Describe at least two components of a dementia friendly community

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### TALKING POINTS:

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

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

## SLIDE 3:

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

- Dementia is a decline in mental ability that interferes with daily life
- Alzheimer's disease is the most common form of dementia
  - Progressive loss of memory and brain function
  - Requires increasing aid and assistance
  - No cure and limited treatment options
- Huge financial and emotional burden
- Public health plays important role in addressing Alzheimer's disease

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### TALKING POINTS:

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

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

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

**Alzheimer's disease** is the most common cause of dementia. Alzheimer's is a progressive disease that ranges from mild to severe cognitive impairment that occurs on a continuum over the course of many years, even decades. The term **Alzheimer's dementia** is used to describe the stage of Alzheimer's disease when an individual has observable

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<sup>1</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

symptoms such as memory loss, mood/behavior changes, and difficulty with activities of daily living. There is **no cure** for Alzheimer's. While there are approved drug **treatments**, the goal of existing treatment is to delay or reduce symptoms, not to cure or reverse the course of the disease.

As the person with Alzheimer's loses memory and function, **caregivers**, who are most often family members, are needed to provide increasing amounts of assistance. This assistance can range from helping to manage finances and household tasks to hands-on care, such as bathing, dressing, feeding, and other activities of daily living. Given the nature of the disease and its increasing prevalence, there is a **huge financial, emotional, and physical impact** on people with Alzheimer's, their families, caregivers, and the health care system as a whole.

**Public health** plays an important role in addressing Alzheimer's disease through surveillance, prevention, detection, and support of **dementia-capable systems**.

In this presentation, we will be focusing on **dementia capable systems and dementia friendly communities**, both of which involve government and health care agencies, organizations, and communities accommodating the needs of people with dementia and their caregivers through education, services, and support within their community.

## SLIDE 4:

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### Alzheimer's: A Larger Context<sup>2</sup>

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

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### TALKING POINTS:

Alzheimer's and other dementias affect not only the individual but also families and communities. **Communities** have many people living with Alzheimer's and other dementias and many others who are at risk for developing these conditions. As many as 70% of people living with Alzheimer's and other dementias live in the community, with 74% of those individuals living with a caregiver. Family caregivers also need support. Professionals who interact with both individuals with dementia and their caregivers need training on how best to provide services and support to both.

Individuals with dementia and their caregivers rely on many **care services**, including health care, support services (in-home, community, and long-term care), and government agencies to meet their ongoing and changing care needs.

People with Alzheimer's and other dementias also interact with and depend on community services and businesses such as transportation, grocery stores, places of worship, banks, and law enforcement.

Later in the module, you will learn how a **public health response** to the epidemic considers the unique needs of people with dementia and their caregivers on state and local levels, within institutions, and across communities.

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<sup>2</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

## SLIDE 5:

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### Discussion Questions

Imagine you or someone you care about has Alzheimer's or dementia.

What might be some of your concerns or fears about going out in your community?

How could those be addressed at a community level?

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### TALKING POINTS:

**Ask:** Imagine you or someone you care about has Alzheimer's or dementia.

What might be some of your concerns or fears about going out in your community?

How could those be addressed at a community level?

**Open responses.**

**Video: Alzheimer's Society (UK)** (3:35 minutes)

[Brief video shows simulation of what it might be like for someone with dementia to navigate everyday life in her community.](https://www.youtube.com/watch?v=Fz8ACEu7Lho)

<https://www.youtube.com/watch?v=Fz8ACEu7Lho>

## SLIDE 6:

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### Two Frameworks: Dementia Capable System and Dementia Friendly Communities<sup>3</sup>

- Designed to meet the needs of older adults within a community
- Aim to help older adults remain independent and in the community as long as possible
- Bring together community members and key stakeholders to focus on accommodations, provide support, and improve quality of life for older adults

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#### TALKING POINTS:

Given that the population of adults over age 65 is rapidly increasing, there are efforts at the national and international level to put in place infrastructure, policies, and practices from the local level upward to support older adults and their families. The vast majority of older adults want to remain independent in their homes and in their communities for as long as possible. This means having communities prepared to meet the changing and increasing needs of older adults in terms of community resources and infrastructure, health care, and social services.

Many of the issues discussed in this presentation tie into the concept of **dementia friendly communities** and what it means to have **dementia capable systems** in place that help communities be more accommodating to people with dementia and dementia caregivers.

These two frameworks aim to help communities plan for and address the challenges associated with the growing impact of dementia. While also used in other countries, in the United States, the concept of **dementia friendly communities** is intended to involve multiple sectors by

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<sup>3</sup> Turner, N., Morken, L. (2016) *Better Together: A Comparative Analysis of Age-Friendly and Dementia Friendly Communities*. AARP International Affairs. Retrieved from <https://www.aarp.org/content/dam/aarp/livable-communities/livable-documents/documents-2016/Better-Together-Research-Report.pdf>

Image source: Dementia Friendly America

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bringing together community members and key stakeholders to enhance support and improve quality of life for all affected by dementia. The federal Administration for Community Living has also championed the **dementia capable system** framework, which may focus on a single sector or organization.

Both frameworks are designed to meet the needs of the rapidly increasing population affected by dementia (including caregivers) by preparing communities, health systems, and governments.

Both aim to help people living with dementia remain independent and in the community as long as possible.

Each of these frameworks has the potential to help communities begin to address the overall needs of older adults and the unique needs of people with dementia and their caregivers.

## SLIDE 7:

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### Dementia Friendly Communities<sup>4,5</sup>

- Health care, community services, resources
- Safe and accessible
  - Transportation
  - Mobility
- Respectful and supportive
- Public education and workforce training
- Technology
  - GPS, GIS
  - Registry

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### TALKING POINTS:

In the **dementia friendly community** framework, people with dementia, their family, and caregivers are understood, respected, supported, and able to continue to engage with and contribute to their community. The effort to become **dementia friendly** is made at a community level and requires planning and participation from all sectors with involvement of those with dementia and dementia caregivers.

Although overlap exists between the concepts of dementia *capable* and dementia *friendly*, a dementia friendly community encompasses a broader goal of supporting a higher quality of life for people with dementia beyond simply meeting their physical and health needs.

In this framework, dementia friendly communities would have:

- Access to **quality health care and community services**. While encompassing the same aspects of

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<sup>4</sup> U.S. Administration for Community Living/Administration on Aging. (2014) *Dementia-Capable States and Communities: The Basics*.

<sup>5</sup> The Gerontological Society of America. (2015) *Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future*.

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

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

dementia capable systems, dementia friendly communities offer:

- Resources and supports that are **geographically, financially, and culturally available and accessible**
- **Support services and activities**, such as educational sessions regarding symptoms, disease processes, self-care, and providing care, as well as support groups and dementia friendly social events that are readily available throughout the community
- **Safety and accessibility:** People can live **safely**, with as much independence as possible

This concept includes **public transportation, walkability** for leisure and to complete daily tasks, minimizing confusion when moving from place to place, and ensuring **safety**

- **Mobility** considerations that may include:
  - Age-friendly pavements
  - Adequate signage
  - Safe pedestrian crossings
  - Trained safety personnel
  - Welcoming open spaces, including squares, parks, and playgrounds
- **Public education and workforce development:** In these communities, residents, agencies, businesses, health care facilities, places of worship, and general service providers are learning about dementia through education and awareness efforts, so they can better assist people with the condition and their caregivers as they go about their daily lives
- **Technology** may also play a role in the creation of dementia friendly communities:
  - **Geographic Information Systems (GIS) and Global Positioning Systems (GPS)** can help people navigate their community while still allowing family or caregivers to track their whereabouts

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

- **Community registry:** Law enforcement can also create or partner with a voluntary registry for individuals with dementia

These registries have the name, home address, and contact information for family members or care partners should the individual with dementia need help from or interact with law enforcement

Evaluations are needed to better understand the utility of the dementia-friendly community framework in helping communities develop these attributes.

### **Additional reading:**

<https://alz.org/media/Documents/spotlight-dementia-friendly-communities.pdf>

## SLIDE 8:

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### Dementia Capable Systems<sup>6, 7</sup>

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

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### TALKING POINTS:

Part of creating a dementia friendly community is ensuring there are **support services and infrastructure** in place to meet the needs of individuals with Alzheimer's and dementia and their caregivers. Having this support in place within the community is referred to as having **dementia capable systems**.

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

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

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<sup>6</sup> 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.

<sup>7</sup> Tilly, J., Weiner, J., Gould, E., and O'Keefe, J. (2011) *Making the Long-Term Services and Supports System Work for People with Dementia and Their Caregivers*. Washington, DC: Administration for Community Living. Retrieved from <https://acl.gov/sites/default/files/triage/BH-Brief-Dementia-Capable-Basics.pdf>

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

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

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

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

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

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

## SLIDE 9:

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### Dementia Capable: Public Health<sup>8</sup>

- Analyzing community support needs
- Building connections to support services and programs
- Providing Workforce training
- Establishing Dementia friendly communities

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### TALKING POINTS:

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

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

Each of these will be discussed in more detail.

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<sup>8</sup>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.

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## SLIDE 10:

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### Dementia Capable: Public Health (continued)<sup>9,10</sup>

- Use data to inform the public health program and policy response to:
    - Cognitive health
    - Cognitive impairment
    - Caregiving
  - Evaluate training and programs
  - Estimate gap between workforce capacity and demand for services
- 

### TALKING POINTS:

Public health utilizes data from available surveillance strategies and sources (local, state, national, and even global) to guide programs, priorities, and policies.

Public health practice can actively incorporate evaluation into training and programs. Programs (such as support programs for caregivers) can evaluate how accessible, effective, and impactful the program is for participants. Evaluation is key to creating and sustaining an effective program.

The number of people with Alzheimer's is projected to triple in the next 35 years, with the number of caregivers also continuing to rise. As these populations grow, the workforce that provides support will also need to grow. This workforce includes professions such as:

- Adult day workers
- Community-based and long-term care services
- Social workers
- Occupational therapists
- Healthcare professionals

Public health can prepare the workforce to provide support to people with Alzheimer's and their caregivers by estimating demand for different types of professionals and identifying gaps in workforce readiness.

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<sup>9</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>10</sup> 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.

**SLIDE 11:**

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**SUPPORT SERVICES & PROGRAMS**

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**TALKING POINTS:**

Public health can inform the design of **support services and programs** for people with Alzheimer's and other dementias.

**SLIDE 12:**

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**Discussion Question**

What kinds of support services might people with Alzheimer's and their caregivers need?

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**TALKING POINTS:**

**Ask:** What kinds of support services might people with Alzheimer's and their caregivers need?

**Open responses.**

## SLIDE 13:

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### Support Services: Alzheimer's<sup>11,12</sup>

- Support groups
- Wellness programs
- Care services, including in-home care
- Legal and financial services
- Residential care
- Transportation
- Adult day care

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### TALKING POINTS:

Individuals with Alzheimer's and dementia may **require** varying levels of **care and support from numerous sources**, including:

- **Support groups and socialization programs:** aimed at persons with mild (early) stage Alzheimer's disease, these groups can provide social support and engagement, help with planning for future needs, and provide general guidance and support for individuals and caregivers
- **Wellness programs:** includes nutrition and physical activity programs, physical/occupational/speech therapy; may also include opportunities for cognitive stimulation, such as creative arts or intergenerational connections

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<sup>11</sup> US. Administration on Aging. (2011) *Dementia Capability Toolkit*. Retrieved from <https://www.aarp.org/content/dam/aarp/livable-communities/old-learn/health/Dementia-Capability-Toolkit-2011-AARP.pdf>

<sup>12</sup> Tilly, J., Wiener, J., & Gould, E. (2014) *Dementia-Capable States and Communities: The Basics*. Washington, DC: Administration for Community Living. Retrieved from: <https://acl.gov/sites/default/files/triage/BH-Brief-Dementia-Capable-Basics.pdf>

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*Image source:* Pexels.com

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

- **Care services:** includes care managers, chore services, home safety, personal care assistants, and respite
- **Legal or financial services:** financial, health care, and end-of-life planning
- **Residential care:** includes living options with varying levels of care, such as independent living communities, assisted living residences, and nursing homes tailored to people with dementia
- **Transportation:** includes safe driving supports and individual and group transportation options
- **Adult day care:** care for individuals who require regular supervision along with activities for socialization, cognitive stimulation, and physical activity; provides caregivers time to work or fulfill other responsibilities

## SLIDE 14:

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### Examples of Evidence-based Programs<sup>13,14</sup>

- Reducing Disability in Alzheimer’s Disease (RDAD) – University of Washington
  - Focus: teach family caregivers strategies
- Minds in Motion (MIM)
  - Focus: improve function in early stages with mild cognitive impairment
- Sharing History through Active Reminiscence and Photo-imagery (SHARP) - Oregon Health & Science University
  - Focus: neighborhood walking groups to trigger memories and increase social engagement
- Skills2Care – Thomas Jefferson University
  - Focus: occupational therapy-based strategies for caregivers

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### TALKING POINTS:

There are many examples of evidence-based programs for people with Alzheimer’s and dementia and their caregivers.

- **Reducing Disability in Alzheimer’s Disease (RDAD):**  
Developed by the University of Washington, the primary aims of the RDAD program are to teach family caregivers:
  - Strategies to decrease challenging behaviors related to Alzheimer’s and dementia, such as depression, anxiety, agitation, and aggression
  - Methods to engage in and encourage physical activity in order to reduce the physical disabilities that often result in a loss of independence

RDAD consists of 12 hourly sessions, conducted in participants’ homes over three months.

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<sup>13</sup> Alliance for Aging Research. (2012) *Translating Innovation to Impact: Evidence-based Interventions to Support People with Alzheimer’s Disease and their Caregivers at Home and in the Community.*

<sup>14</sup> Oregon Health & Sciences University. (2017) *Preserving Memories to Maintain Cognitive Health.*

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

- **Minds in Motion®:** Minds in Motion is designed to improve or sustain cognitive and physical functioning in persons with mild (early) stage dementia or mild cognitive impairment (MCI). From the Alzheimer Society of Manitoba, the group-based program, delivered in community settings, includes a variety of evidence-based components, including:
  - Cognitive training exercises
  - Physical exercises (Tai Chi and Qi Gong)
  - Creative/community involvement activities (writing, art, photography, etc.)
- **Sharing History through Active Reminiscence and Photo-imagery (SHARP):** Developed by Oregon Health & Science University. This program engages older African American adults in the Portland area to take group walks in familiar neighborhoods.
  - Using designated routes and a smart phone, the walkers are prompted with questions about landmarks to trigger memories of the location
  - The goal was to reduce barriers to activity and engagement within their changing neighborhoods and to increase social engagement
- **Skills2Care®:** This occupational therapy-based intervention for caregivers and individuals with dementia living at home was developed by Thomas Jefferson University. The intervention is designed to reduce caregiver burden, improve caregiver ability to manage daily care challenges, and reduce behavioral symptoms and functional dependence in individuals with dementia. Caregivers are trained in five types of strategies:
  - Communication techniques
  - Environmental modification
  - Task simplification
  - Use of activities to engage individuals with dementia
  - Self-care

A resource with additional evidence-based programs can be found on the National Alzheimer's and Dementia Resource Center site: <https://nadrc.acl.gov/node/140>

**SLIDE 15:**

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**Discussion Question**

What is the role of public health in connecting people to the services they need?

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**TALKING POINTS:**

**Ask:** What is the role of public health in connecting people to the services they need?

**Open responses.**

## SLIDE 16:

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### Public Health: Support Services<sup>15</sup>

- Evidence-based programs and interventions
- Information and referrals
- Identify gaps in available support services
- Funding, space, expertise

---

### TALKING POINTS:

Public health may serve to **provide, connect, and inform** individuals, families, and caregivers about support services within **clinical and community** settings.

Public health agencies and organizations can:

- **Develop and disseminate** evidence-based programs and interventions
- Offer **information and referrals** to specific support services, programs, and sources of information
- **Identify gaps** in available **support services** by reviewing current support services in a community as well as identify and address disparities in services available to underserved populations
- **Provide funding, space, expertise**, or other support for needed programs

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<sup>15</sup> 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:* National Cancer Institute, NCI Visuals Online, Bill Branson (Photographer)

## SLIDE 17:

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### Support Services: Partnerships<sup>16</sup>

- Offices on Aging / Aging and Disability Resource Centers / Area Agencies on Aging
  - Education
  - Caregiver and safety assessments
  - Support programs
  - Resources
- Non-profit organizations
- Residential care facilities

---

### TALKING POINTS:

Public health is also in a unique position to strengthen **partnerships** within the community to build **dementia capable systems** and ensure that needed services and resources are available.

- **Offices on Aging/Aging and Disability Resource Centers/Area Agencies on Aging** can partner with local public health departments to **assess** community needs, **develop** programs and supports, and **provide** referrals.  
  
Staff may be knowledgeable about Alzheimer's and dementia, offer **caregiver and safety assessments** and family **caregiver supports**, and have information about **resources** and **programs** available in the community for individuals with dementia and their families.
- **Non-profit organizations**, such as the **Alzheimer's Association**, have experts in the field of dementia care with a wide variety of information and educational materials and programs to support individuals, families, and caregivers.

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<sup>16</sup> ACT on Alzheimer's. (2014) *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

*Image source:* Centers for Disease Control and Prevention, Amanda Mills (Photographer)

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

- Other non-profits, such as **faith-based organizations** and **civic groups**, can be partners that may co-sponsor educational events, distribute information, offer services, provide a place for caregiver support groups to meet, etc.
- **Residential care facilities** may be able to reach out to other health care and business partners in the community to promote awareness, support program development, and initiate dementia friendly policies.

**SLIDE 18:**

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**WORKFORCE TRAINING**

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**TALKING POINTS:**

Public health may also play a key role in training the workforce – professionals in health-related fields as well as others – to better understand, identify, and respond to individuals with Alzheimer’s and dementia and their caregivers.

## SLIDE 19:

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### Workforce Training

- Health care
  - Direct care
  - Public health
  - First responders
  - Other support services: transportation, customer service, faith-based organizations
- 

### TALKING POINTS:

Certain professions may provide service and support to people with Alzheimer’s disease and their caregivers in a variety of ways. The workforces that would benefit from training and education include:

- **Health care workforce:** including primary care physicians, specialists (neurologists, geriatricians, psychiatrists), nurses, community health workers, social workers, psychologists, pharmacists, and dentists
- **Direct care professionals:** the workforce that provides the majority of the paid daily care (such as helping with bathing, dressing, housekeeping, food preparation, etc.) for people with Alzheimer’s and dementia; includes nurse aides, home health aides, and personal and home-care aides
- **Public health** workforce including health educators, evaluators, biostatisticians, epidemiologists
- **First responders:** including law enforcement, fire, emergency response teams, emergency medical technicians (EMTs), and adult protective services
- **Other** professions: including **transportation**, **customer service**, and **faith-based** or spiritual organizations

Each of these will be discussed in more detail.

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

**SLIDE 20:**

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**Discussion Question**

What training should health care and direct care professionals receive?

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**TALKING POINTS:**

**Ask:** What training should **health care and direct care professionals** receive?

**Open responses.**

## SLIDE 21:

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### Workforce Training: Health Care & Direct Care<sup>17</sup>

- Basics of dementia
- Benefits of early diagnosis
- How to address physical, cognitive, emotional, behavioral symptoms
- Assisting caregivers
- Managing co-morbidities
- Use of validated assessment tools (health care)

---

### TALKING POINTS:

The health care and direct-care workforce need **training and education** on identifying and caring for someone with Alzheimer's and dementia including:

- The basics of **dementia**, including recognizing early warning signs
- The benefits of **early diagnosis**
- How to address the physical, cognitive, emotional, and behavioral **symptoms** of the disease to provide person-centered care. **Person-centered care** is a philosophy of care built around the needs of the individual with dementia and depends on interpersonal relationships with caregivers. Caregivers get to know the complete person-likes/dislikes, values/beliefs, who they are- past and present and build a caring relationship that can enhance person's quality of life and wellbeing
- How to assist **caregivers** as they cope with the physical and emotional aspects of their caregiving responsibilities

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<sup>17</sup> Fazio, S., Pace, D., Flinner, J. & Kallmyer, B. (2018) The Fundamentals of Person-Centered Care for Individuals With Dementia. *The Gerontologist*, 58(1), S10–S19. <https://doi.org/10.1093/geront/gnx122>

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

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

- Management of **co-morbidities** (such as diabetes, hypertension, and heart disease)
- The availability and use of **tools** and **guidelines** to identify dementia, including validated cognitive assessment tools (health care providers)

**SLIDE 22:**

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**Discussion Question**

What training should public health professionals receive?

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**TALKING POINTS:**

**Ask:** What training should **public health professionals** receive?

**Open responses.**

## SLIDE 23:

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### Workforce Training: Public Health

- Alzheimer's as a public health priority
- Importance of early detection
- Cognitive health and risk reduction
- Types and availability of resources and supports
- Caregiver burden and needs
- Surveillance
- Health disparities
- Unique issues (stigma, abuse, advance planning)

---

### TALKING POINTS:

Public health plays a key role in surveillance, education, and prevention related to Alzheimer's.

Training and education priorities for public health include:

- Understanding Alzheimer's as a **public health priority**
- The importance of **early detection**
- **Cognitive health** and **risk reduction** for Alzheimer's
- **Types and availability of resources and supports** for individuals with Alzheimer's and dementia
- Needs and burden of **caregivers**
- Tracking **surveillance data** on cognitive decline and caregiving
- **Health disparities** related to Alzheimer's and dementia
- Issues unique to Alzheimer's and dementia, including **stigma**, potential for **abuse**, and the need for **advance planning**

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

**SLIDE 24:**

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**Discussion Question**

What training should first responders receive?

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**TALKING POINTS:**

**Ask:** What training should **first responders** receive?

**Open responses.**

## SLIDE 25:

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### Workforce Training: First Responders

- Situations involving stress or fear
- Training needs:
  - Identifying Alzheimer's and dementia
  - Effective interaction/communication
  - Resources
  - Registries, technologies

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### TALKING POINTS:

First responders such as police, emergency medical personnel, and fire fighters may have first-hand contact with individuals with Alzheimer's and other dementias during situations that involve stress or fear, such as:

- **Wandering**, being **lost**, or **disoriented**
- **Natural** or **other disasters** that may displace individuals with Alzheimer's and/or separate them from their usual caregivers
- Being subjected to physical, emotional, or financial **abuse** which is more likely to occur and can be harder to detect when an individual with dementia is no longer able to advocate for themselves or may be unable to recognize behaviors as abusive
- Being reported to law enforcement for **improper behavior**, such as leaving a place of business after forgetting to pay for purchase

First responders and law enforcement need **training** on:

- How to **identify** someone with Alzheimer's and dementia
- How to **interact** and **communicate** with people with Alzheimer's in various situations (especially ones that are stressful for the person)
- **Resources** to call upon for assistance or information

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

- Existence of **special needs registries** or other technologies that may assist in locating individuals, their places of residence, or their caregivers
- How to recognize the signs of abuse or neglect and notify **adult protective services** which investigates cases of abuse, neglect, or exploitation of older adults or disabled adults

**Supplemental reading:** Case study on EMS workers in CO

<https://alz.org/media/Documents/case-study-co-ems-training.pdf>

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

## SLIDE 26:

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### Workforce Training: Other Professions

- Public transportation, customer service, faith/spiritual communities, etc.
  - Awareness
  - Recognizing need for help
  - Resources
  - Communication
  - Ways to assist and support

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### TALKING POINTS:

Many other professionals come into contact with people with Alzheimer's disease and require different levels of information:

- **Public transportation:** For individuals with dementia, navigating public transportation can be very challenging. Operators and drivers need to be aware of the special challenges faced by individuals with dementia, as well as how to recognize the signs that someone may need help
- **Customer service:** Those in service positions may be trained to recognize when they are dealing with someone with possible Alzheimer's and dementia and how to best communicate with them and meet their needs
- **Faith or spiritual communities:** These communities can be an important source of support and engagement for people with dementia, their families, and their caregivers. Church liaisons and volunteers may be trained to assist and support community members living with dementia

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

**SLIDE 27:**

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**CAREGIVER NEEDS AND SUPPORT**

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**TALKING POINTS:**

Usually, the very first line of support and care for the person with dementia is a family caregiver. The family caregiver is part of the “workforce” in the sense that they have definite training needs. At the same time, they also need support themselves as they care for someone living with dementia.

Caregiving can be a rewarding experience, but also one that is high stress. As dementia progresses, caregivers often face a steep learning curve as well as the need for extra support as the person living with dementia needs more and more care. Part of making a dementia friendly community is putting in place supports and services for the caregiver. Let’s look at the needs of the dementia caregiver.

## SLIDE 28:

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### Support Services: Caregivers<sup>18,19</sup>

- Education/information/training
  - Alzheimer's/dementia
  - Behavioral management
  - Available resources
  - Self-care

---

### TALKING POINTS:

When someone has Alzheimer's or dementia, family members and friends who are caregivers will face an ever-changing set of needs that increase as the disease progresses. The majority of people with Alzheimer's and dementia live in the community with many living independently until it becomes unsafe for them to continue living alone.

In 2017, **16 million** family members and friends provided **18.4 billion** hours of unpaid care to people with Alzheimer's and other dementias. It is usually a daughter or daughter-in-law who takes on the role of being the primary caregiver for the individual.

As the disease progresses, the individual becomes more reliant on others for all their care needs. Many family caregivers try to meet these care needs themselves as long as possible, often reducing work hours or quitting their jobs as the level of care increases. Many arrange for the help of paid caregivers to provide additional assistance in the home, until the individual's care needs exceed what can safely and continuously be provided in the home.

Most family caregivers are initially unprepared for the role. There is much to learn about the disease itself. At the same time, the caregiver is also taking on more of the individual's

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<sup>18</sup> ACT on Alzheimer's. (2014) *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

<sup>19</sup> Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. Chicago, IL: Alzheimer's Association; 2018.

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

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life routines such as house maintenance, financial management, medication management, and eventually activities of daily living such as bathing, dressing, and eating.

These responsibilities typically add up to the caregiver needing support services for the person living with dementia and themselves, as well as training and ongoing education.

Support services and programs that have been found to be most effective for caregivers include multiple components to address different needs:

- **Education/information/training on:**
  - Alzheimer's and dementia and its effects on behavior throughout the continuum
  - **Training on working with dementia-related behaviors** designed to train caregivers to use specific techniques to manage behaviors that can be challenging (such as agitation, repetition, aggression, wandering)
  - Information on the availability of **resources**
  - **Self-care**, such as stress management, using respite services

## SLIDE 29:

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### Support Services: Caregivers (continued)<sup>20,21</sup>

- Counseling/support groups
  - Case management
  - Respite services
- 

### TALKING POINTS:

Support services for caregivers vary based on the individual need, but some of the most common forms of support include emotional support through individual counseling or support groups; care management to help manage the needs and coordinate care; and respite care which provides temporary time off.

- **Counseling/support groups:**
  - Individual and family **counseling**
  - **Support groups** that have been found to have the most positive outcomes focus on specific objectives, such as teaching certain skills or strategies
- **Care management:** helping to identify and manage care needs, and coordinate across care systems and providers. Professional care managers can help alleviate some of the tasks associated with caregiving, such as managing medical appointments, securing resources and services, and finding long term care if needed
- **Respite services:** provides care for a person with Alzheimer's disease on a temporary basis, providing much-needed time off for a family caregiver

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<sup>20</sup> ACT on Alzheimer's. (2014) *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

<sup>21</sup> 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:

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### Conclusion: Dementia Capable and Dementia Friendly

- States/communities play significant role
- Dementia capable systems and dementia friendly communities
  - Analyze community support needs
  - Support services and programs
  - Workforce training
  - Caregiver training and support

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### TALKING POINTS:

In conclusion, states and communities can play an active role in reducing the burden of the Alzheimer's and dementia. Two approaches are creating **dementia capable systems** and **dementia friendly communities**. The concepts are similar and can overlap, but the focus of both is on accommodating those with dementia and their caregivers through providing support and services within their communities. **Public health** must take an active role in fostering dementia capable systems and dementia friendly communities through:

- Analyzing community support needs for those with dementia and their caregivers, and using those findings to design effective programs, policies, and best practices
- Serving to provide, inform, and connect individuals and caregivers to **support services and programs**
- Designing and implementing **workforce training** to ensure workers across a wide range of professions are able to identify and meet the needs of people with Alzheimer's and dementia
- Providing caregivers with the support and training they need to better care for the person living with dementia
- Supporting the creation of **dementia friendly communities** that help people with Alzheimer's and dementia remain safe and as independent as possible

## SLIDE 31:

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### For More Information

For more information, please visit:

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

CDC's Alzheimer's Disease and Healthy Aging Program at <https://www.cdc.gov/aging/>

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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> 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 32:

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### Competencies

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

- I.6.7 Promote and apply the use of appropriate forms of evidence-based interventions and technologies for older adults, their families, and caregivers
- II.4.5 Provide the following groups information and education in order to build a collaborative aging network:
  - Key persons in the community (police officers, firefighters, mail carriers, locale service providers, and others)
  - Aging workforce professionals and personnel (paid and unpaid; full-and part-time) in the field of aging

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

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

#### Council on Linkages Between Academia and Public Health Practice:

- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence, and innovation)

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**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):**

- I.6.7 Promote and apply the use of appropriate forms of evidence-based interventions and technologies for older adults, their families, and caregivers
- II.4.5 Provide the following groups information and education in order to build a collaborative aging network:
  - Key persons in the community (police officers, firefighters, mail carriers, locale service providers, and others)
  - Aging workforce professionals and personnel (paid and unpaid; full-and part-time) in the field of aging

### **Council on Education for Public Health (CEPH) Foundational Competencies**

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

### **Council on Linkages Between Academia and Public Health Practice:**

- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence, and innovation)

## SAMPLE TEST QUESTIONS

**1- Which professions need to be knowledgeable about dementia?**

- a. Health care workers (nurses, direct care providers)
- b. Public sector workers (government- federal/local)
- c. Private sector workers (for profit/non-profit)
- d. A & B
- e. All of the above

**Answer: E**

**2- Training and education priorities for public health include:**

- a. The importance of early detection
- b. Needs and burden of caregivers
- c. Tracking surveillance data on cognitive decline and caregiving
- d. All of the above
- e. B & C

**Answer: D**

**3- What support services do people with Alzheimer's need?**

- a. Wellness programs
- b. Financial planning services
- c. Support groups
- d. A & C
- e. All of the above

**Answer: E**

**4- The term "dementia capable" means all of the following *except*:**

- a. A device able to be used by someone with dementia
- b. Accommodating the needs of those with dementia
- c. Able to identify people with dementia
- d. Support systems for people with dementia

**Answer: A**

**5- Some states have registries of people with Alzheimer's for surveillance, monitoring and research.**

- a. True
- b. False

**Answer: A**

## Selected Case Studies- Module 4

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

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

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

### Discussion Questions:

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

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

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

### Description:

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

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

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

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can no longer do everything they once did during the holidays; however, they still feel the sense of missing out and being excluded.

### Discussion Questions:

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

### 3. "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

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

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 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 can 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. “Can Technology Ease the Burden of Caring for People with Dementia?” NPR (2015).

- **Audio/Transcript Link:**  
<http://www.npr.org/templates/transcript/transcript.php?storyId=417205451>
- **Run Time:** 4:35 minutes (audio)
- **Key Terms:** care givers burden, financial burden, healthcare system, family support, technology, monitoring systems, long term care
- **Modules:** 2, 3, 4

##### Description:

Aurora is 78 years old and lives with her husband, Arturo, in a small apartment in San Rafael. Aurora’s daughter, Maria, comes by their apartment almost daily to help her mother bathe, grocery shop, do laundry, provide medical care, and do many other tasks around the house to help her father and care for her mother.

Early in her Alzheimer’s disease diagnosis, Aurora began wandering at night. Afraid that she might wander into the street, Arturo, began sleeping on the floor in front of the bedroom door in order to keep Aurora from leaving the apartment. Maria had the idea of attaching wind chimes to the door so that Arturo can hear when the door is opened and closed.

Maria and Arturo are currently able to provide all the necessary care for Aurora to live safely in her own home. However, caring for people living with Alzheimer’s tends to be mentally and financially exhausting. As Aurora’s Alzheimer’s progresses, her safety in the apartment becomes an increasing concern.

The story discusses ways that technology, such as remote sensor monitoring systems, can help people with dementia stay independent longer while giving caregivers a way to monitor activity and safety.

##### Discussion Questions:

- What are some technologies available to help monitor the health of people diagnosed with Alzheimer’s disease?
- What are ethical dilemmas about these kinds of technologies that may be considered invasive of an individual’s privacy and health?
- What are other ideas for technology that will allow for increased safety and prolonged independence of older adults with Alzheimer’s disease?
- What is the role of public health with assistive technologies?

## 5. “Dementia Village’ Inspires New Care,” CNN (2013).

- **Video Link and Article:**  
<https://edition.cnn.com/2013/07/11/world/europe/wus-holland-dementia-village/index.html>
- **Run Time:** 3:27 minutes (accompanying news article included in link)
- **Key Terms:** long term care, stigma, financial burden, caregiver burden, community, cultural context, increasing aging population, healthcare system, health policy
- **Modules:** 4

### Description:

Hogewey, or “Dementia Village” as it is known, is a facility created in 2009 in Weesp, Netherlands that is home to 152 residents with dementia. The village is comprised of dormitories uniquely decorated like patients’ homes, a grocery store, restaurants, theater, salon, courtyards, and gardens for residents to enjoy. There is only one exit at the facility, which allows the many skilled caretakers to come and go while the residents are free to wander safely inside the village. The creator of the nursing home, Yvonne van Amerongen, has taken considerable time to create a space unique to each resident that reminds of them of their early life.

While this facility seems ideal to many, some question the ethics of creating a “fake” reality or “duping” the residents. For example, residents can go to the supermarket and not worry about paying. The staff will take care of payment later, without including and potentially confusing the resident. Yvonne defends the model of care, explaining that the facility is the true reality of the residents and provides them peace of mind.

Additionally, this facility costs the same amount of money as any other nursing home in the Netherlands due to the state health care system that all residents pay into and covers expenses such as this as individuals’ age.

### Discussion questions:

- What are the pros and cons of living in a community like this?
- Discuss the criticism that Hogewey is “duping” the residents.
- Could you see this model of care being implemented in the US? Why or why not?
- How can a community like Hogewey impact the family of residents?
- What would you change (or not change) about Hogewey?

## 6. “Alive inside: A Story of Music and Memory Featurette,” Movieclips Indie (2014).

- **Video Link:** <https://www.youtube.com/watch?v=8HLEr-zP3fc>
- **Run Time:** 6:29 minutes
- **Key Terms:** cultural context, music, long term care, family relationships, healthcare system, increasing aging population, loss of identity, technology, community
- **Modules:** 3, 4

### Description:

This video clip demonstrates how music can be used as a form of therapy for individuals diagnosed with Alzheimer’s disease. Yvonne Russell, a recreation therapist discusses how music has positively impacted one of her patients, Henry. Henry has been in a nursing home for ten years after he began having seizures and his wife was no longer able to care for him at home. His daughter recalls how her father was always singing and dancing when she was a child. At the nursing home, Henry is typically unresponsive and spends most of the day looking down sitting in his chair, unable to carry on a conversation or speak more than a few words. After learning about his love of music, Yvonne had all of Henry’s favorite songs downloaded on to an iPod. When she puts the headphones on Henry and plays the music, he immediately sits up, eyes go wide and begins to sing along and dance in his chair. After listening to the music, Henry is asked a series of questions and is able to respond quicker and with more detail than usual. He recalls the name of his favorite singer and even sings his favorite song.

### Discussion Questions:

- How did music impact Henry?
- Discuss ways that caregivers and care facilities can better engage individuals with Alzheimer’s.
- What should public health professionals take away from this case study?

## 7. My Typical Day

- **Website Link:** <http://www.mytypicalday.org/>
- **Key Terms:** mild cognitive impairment, caregiving, photograph diary, identity
- **Module:** 2, 3, 4

### Description:

This photography project features seventeen older adults with mild cognitive impairment (MCI) as they share their world with researchers through images, rather than words. The project is a collaboration of Penn Memory

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

Center, Penn Healthy Brain Research Center, Penn Medicine CAREs grant, and Penn Neurosciences. Explore the stories of each individual.

### Discussion Questions:

- In what ways has life changed since their diagnoses?
- How have they reacted to their diagnoses? Positively? Negatively?
- How have they adapted their everyday routines?
- What support do they have?
- What changes have they noticed?
- What role do their families and friends play?

## 8. “Tribal Outreach Video –A Project of the UW Alzheimer’s Disease Research Center and Partnerships for Native Health,” Vimeo (2019).

- **Video Link:** <https://vimeo.com/314071595>
- **Run Time:** 5:30 minutes
- **Key Terms:** American Indian, Native Alaskan, oral tradition, memory loss, research, diversity
- **Module:** 3, 4

### Description:

Becky Bendixon talks about her mother’s diagnosis of Alzheimer’s disease. Becky first noticed that her mother was experiencing some memory loss when she struggled to fill out a form with her basic information. She then realized that something was seriously wrong when her mother’s pharmacy called because her mother was having issues remembering to take her medications, putting her life in danger. Becky describes the importance of oral tradition in her culture and how memory loss due to Alzheimer’s prevents generations from passing down these oral traditions, resulting in a loss of culture and identity of the community. Researchers at the University of Washington Alzheimer’s Disease Research Center discuss their goal of increasing representation of American Indian and Alaska Native populations in their research.

### Discussion Questions:

- Why is cultural humility and respect important in public health?
- Why is diversity of participants important in Alzheimer’s disease research?
- How might Becky’s community and culture change if Alzheimer’s disease becomes more prevalent?

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The following case studies (10-14) are pulled directly from the Health Brain Initiative 2018-2023 Road Map, which was developed by the Alzheimer’s Association and the Centers for Disease Control and Prevention (CDC) to advance cognitive health as an integral component of public health.

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

### 9. “Improving Early Detection during Medicare Annual Wellness Visits,” Healthy Brain Initiative Road Map: Utah

- **Key Terms:** early detection, cognitive impairment, screening, providers, assessment tools
- **Modules:** 3, 4
- **Supplemental Video:** start at 33:00 minutes and end at 47:20 minutes.  
[https://www.youtube.com/watch?v=O\\_sQ4arm8UU&index=19&t=0s&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU](https://www.youtube.com/watch?v=O_sQ4arm8UU&index=19&t=0s&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU)
- **Supplemental materials:** Healthy Brain Initiative Roadmap
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-executive-summary.pdf>

#### Description:

Utah is one of the most rural and fastest growing states in America. Currently, about 11% of the state’s three million residents is aged 65 or older, and the state has about 30,000 people with Alzheimer’s dementia, which is expected to rise 40% to 42,000 by 2025. Diagnoses of dementia in later stages may lead to higher levels of disability while receiving care, delays in accessing timely primary care, lack of care coordination, and duplication of services. To improve early detection of cognitive impairment, a focus of *Utah’s State Plan for Alzheimer’s and Related Dementias*, the Utah Department of Health (UDOH) contracted with HealthInsight, a quality improvement organization. HealthInsight interviewed providers about their experiences and processes conducting cognitive assessments during the Medicare Annual Wellness Visit (AWV). While some providers reported performing routine cognitive assessments during the AWV, others reported screening only under certain conditions, such as when patients request assessment or when patients have specific risk factors for cognitive decline, etc. Providers also expressed a need for better tools to detect early stage memory loss. The resulting report, *Cognitive Assessments during Medicare Annual Wellness Visits*, was a collaborative

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

product from HealthInsight; UDOH; the Center for Alzheimer’s Care, Imaging and Research at the University of Utah; and Intermountain Medical Center.

Actions in the Healthy Brain Initiative Road Map include improving healthcare providers’ ability to recognize the early warning signs of dementia and knowledge of validated cognitive assessment tools. As a step in this process, UDOH sent the study report to all Utah primary care physicians, along with a list of resources for people with cognitive impairment and a recommendation from UDOH’s executive director for routine cognitive assessment during the AWV using the Mini-Cog as the primary assessment tool, followed by the Montreal Cognitive Assessment tool (MoCA).

The project deepened UDOH’s understanding of some challenges that physicians face in assessing cognition during the AWV, one of which is uncertainty about which validated tool to use. Receiving clear recommendations from UDOH’s executive director may begin increasing physician use of the tools during AWVs or other occasions in which a physician has concerns about potential cognitive impairment. Use of validated early detection tools helps physicians assess cognitive functioning and detect potential concerns early, the first step in increasing early diagnoses. With some legislative support, UDOH plans to continue collaborating with HealthInsight to develop:

- Cognitive assessment training for primary care physicians and their office staff that will include use of recommended tools and workflow improvement techniques to instill a reliable, repeatable process in clinics; and
- Cognitive health and wellness toolkit to help health professionals navigate the cognitive assessment process, including assessment, diagnosis, referrals, and community resources.

### Discussion Questions:

- What stakeholders did the Utah DOH involve in this initiative?
- Why is early detection of cognitive impairment important?
- Describe some of the barriers to early detection of cognitive impairment and the recommendations that came from this evaluation to overcome those barriers.
- Why is it important that public health professionals conduct evaluations like this?
- How does this study align with the Health Brain Initiative Road Map goals?

## 10. “Preparing First Responders for Interactions with People with Dementia,” Healthy Brain Initiative: Colorado

- **Key Terms:** EMS, healthcare system, stigma, first responders, increasing aging population, community outreach, training, education, cultural context
- **Modules:** 3, 4
- **Supplemental Materials:** <https://www.alz.org/media/Documents/case-study-co-ems-training.pdf>
- **Supplemental materials:** Healthy Brain Initiative Roadmap
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-executive-summary.pdf>

### Description:

Emergency Medical Service (EMS) providers receive many calls to assist people with Alzheimer’s and other dementias. However, they often have little or no formal training to prepare them for the unique physical, behavioral, and communication challenges related to dementia.

To develop a dementia-competent workforce throughout Colorado, the Colorado Department of Public Health and the Environment (CDPHE) partnered with the Alzheimer’s Association Colorado Chapter to deliver its *Approaching Alzheimer’s: First Responder Training Program*. CDPHE marketed the availability of the free, in-person training through its internal networks and all 11 of Colorado’s Regional Emergency and Trauma Advisory Councils.

The training helps first responders serve people with Alzheimer’s in situations involving wandering, disasters or other emergency situations, abuse or neglect, “shoplifting” because they forgot to pay, and driving. At the completion of training, participants receive a poster—*Tips for EMS Working with People with Alzheimer’s*—to display and reinforce effective responses.

See the supplemental material link to learn more about this example of public health workforce education.

### Discussion Questions:

- Why is it important that EMS providers have formal training on assisting people with Alzheimer’s and other dementias?
- What other professionals or community members may benefit from this formal training?
- Discuss the ways that public health providers can expand upon or improve this program.

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- Review the *Tips for EMS working with people with Alzheimer’s* listed in the supplemental material and discuss the “do’s” and “don’ts” of interacting with someone with Alzheimer’s disease.
- How does this example align with the Health Brain Initiative Road Map goals?

### 11. “Encouraging Advance Care Planning for People with Dementia,” Healthy Brain Initiative: Maryland

- **Key Terms:** increasing prevalence, increasing aging population, family support, caregiver burden, policy, healthcare, advance directive, end of life decisions, education, community outreach, long term care
- **Modules:** 2, 3, 4
- **Supplemental materials:** Healthy Brain Initiative Roadmap
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-executive-summary.pdf>

#### Description:

Maryland’s population of people with Alzheimer’s dementia is projected to rise—from 110,000 people in 2018 to 130,000 in 2025, an 18% increase in eight years. As the number of people with dementia rises, so too does the need to assist families in planning for future care needs. The passage of Maryland House Bill 1385 in May 2016 aimed to increase advance care planning among families impacted by dementia. Among other mandates, the law directs the Maryland Department of Health (MDH) to encourage the use of electronic advance directives, develop an electronic platform to connect with healthcare providers at point-of-care using the state-designated health information exchange, and conduct outreach to increase public awareness of the Advance Directive Program. An early assessment found that advance care planning in Maryland is offered primarily through hospitals and hospice providers, with limited free care planning services available through Maryland Legal Aid and Maryland Volunteer Lawyers Service Pro Bono Resource Centers.

To increase advance care planning, MDH collaborated with the Maryland Faith Health Network to lead a year-long series of community engagement activities on electronic advance directives. More than 500 Marylanders learned about advance care planning through health fairs, faith-based events, and end-of-life seminars. In addition, three local health improvement coalitions hosted seven advance-planning educational sessions, with a combined total of 144 participants. More than twice as many participants were able to identify core legal and financial advance planning documents post-session (25%) as pre-session (10%). Also, a greater number of participants (post-session compared

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with pre-session) reported understanding the importance of involving people with cognitive impairment in advance planning.

The medical director of the MDH Center for Chronic Disease Prevention and Control served as a co-chair (along with a representative from the Maryland Department of Aging) of the governor-appointed Virginia I. Jones Alzheimer's Disease and Related Disorders Council during this time. The Council monitors implementation of the *Maryland State Plan on Alzheimer's Disease and Related Disorders*. As a tenet of the Maryland State Plan, MDH used this unique opportunity to engage partners to discuss potential cognitive health education and establish interventions in Maryland's public health programming.

### Discussion Questions:

- Why is it important for an individual diagnosed with Alzheimer's disease to have an advance directive?
- What challenges may arise if an individual with Alzheimer's disease does not have an advanced directive? Consider the different perspectives of the individual, family, and medical providers.
- Discuss the different levels of action taken to promote the use of advance directives among persons with dementia. Who were the key players or stakeholders?
- How does this study align with the Health Brain Initiative Road Map goals?
- Test your knowledge! Do you know what information is included in an advanced directive? Find your states advanced directive to learn more.

## Selected Video Resources- Module 4

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. "Alive Inside: A Story of Music and Memory Featurette," Movieclips Indie (2014).

- **Video Link:** <https://www.youtube.com/watch?v=8HLEr-zP3fc>
- **Run Time:** 6:29 minutes
- **Key Terms:** Alzheimer's disease, music, therapy
- **Modules:** 4

#### Description:

This video clip demonstrates music as a therapy for individuals diagnosed with Alzheimer's disease. Watch as a gentleman with dementia who is largely non-verbal begin singing once he hears his favorite music and becomes more responsive to questions after the music is played.

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

- **Video Link:** [http://www.theconnexion.com/aliveinside/aliveinside\\_index.cfm](http://www.theconnexion.com/aliveinside/aliveinside_index.cfm)
- **Run Time:** 78:00 minutes
- **Key Terms:** music, memory loss, healing
- **Modules:** 4
- **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.

### 3. "Caregivers," HBO (2009).

- **Video Link:** <http://www.hbo.com/alzheimers/caregivers.html>
- **Run Time:** 48:48 minutes (each segment is approximately 10 minutes)
- **Key Terms:** stigma, caregiver relationship, life after caregiving, duties and responsibility, assisted living facilities
- **Modules:** 2, 3, 4
- **Purchase Price:** HBO subscription required

#### Description:

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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.

### 4. “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-lfCRzU&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.

## 5. “‘Dementia Village’ Inspires New Care,” CNN (2013).

- **Video Link and Article:**  
<https://edition.cnn.com/2013/07/11/world/europe/wus-holland-dementia-village/index.html>
- **Run Time:** 3:27 minutes (accompanying news article included in link)
- **Key Terms:** long term care, stigma, financial burden, caregiver burden, community, cultural context, increasing aging population, health care system, health policy
- **Modules:** 4

### Description:

Hogewey, or “Dementia Village” as it is known, is a facility created in 2009 in Weesp, Netherlands, that is home to 152 residents with dementia. The village is comprised of dormitories uniquely decorated like patient’s’ homes, a grocery store, restaurants, theater, salon, courtyards, and gardens for residents to enjoy. There is only one exit at the facility, which allows the many skilled caretakers to

come and go while the residents are free to wander safely inside the village. The creator of the nursing home, Yvonne van Amerongen, has taken considerable time to create a space unique to each resident that reminds of them of their early life. While this facility seems ideal to many, some question the ethics of creating a “fake” reality or “duping” the residents. For example, residents can go to the supermarket and not worry about paying. The staff will take care of payment later, without including and potentially confusing the resident. Yvonne defends the model of care, explaining that the facility is the true reality of the residents and provides them peace of mind. Additionally, this facility costs the same amount of money as any other nursing home in the Netherlands due to the state health care system that all residents pay into and covers expenses such as this as individuals’ age.

### 6. “A Different Visit: Montessori-Based Activities for People with Alzheimer’s/Dementia,” Center for Applied Research in Dementia (2012).

- **Video Link:** <https://www.youtube.com/watch?v=FLDwzgRTbVA>
- **Run Time:** 8:07 minutes
- **Key Terms:** caregivers, emotional health, meaningful visits
- **Modules:** 1, 2, 3, 4

#### Description:

This clip gives suggestions about how to have a meaningful visit with someone who has been diagnosed with Alzheimer’s disease. The video emphasizes focusing on positive feelings. If conversation is not an option, do a simple, safe activity by focusing on the individual’s interests and abilities. The most important thing is for the individual to feel good about the visit at the end. The first half of the clip is applicable to Alzheimer’s disease, and the second half discusses the theory behind their suggestions (Montessori-based activities).

### 7. “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](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

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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.

### 8. “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/](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.

### 9. “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.

### 10. "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>
- **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.

### 11. "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.

## 12. “Living with Memory Loss: In Our Own Words,” The Gathering Place (n.d.)

- **Video Link:** <https://www.phinneycenter.org/memoryloss-film/>
- **Run time:** 5:00 minutes (short version); 16-min. full version also available
- **Key Terms:** community, coping with memory loss
- **Modules:** 4

### Description:

Brief video from the Phinney Center’s The Gathering Place program for people living with early stage memory loss. The video showcases several members of the program sharing their thoughts on living with early stage memory loss.

## 13. “ASTHOConnects Series on Brain Health,” ASTHO (2019).

- **Video Link:** See individual video links below
- **Run Time:** See individual video links below
- **Key Terms:** public health, programs, road map, caregiving, communication, Alzheimer’s disease, brain health
- **Modules:** 2, 3, 4

### Description:

This learning series brings experts in their field to the table to discuss brain health and aging.

### A. “Series on Brain Health: Virtual Open House” (part 1):

- **Video Link:**  
<http://www.astho.org/generickey/GenericKeyDetails.aspx?contentid=20481&folderid=5162&catid=7254>
- **Run Time:** 59:34 minutes
- **Key Terms:** public health, programs, road map, implementation
- **Modules:** 2, 3, 4

### Description:

This webinar highlights national partners at the CDC's Alzheimer's Disease and Healthy Aging Program, Alzheimer's Association, and International Association for Indigenous Aging about the HBI Road Map. Speakers present a national overview of the HBI Road Map, how it was developed, and current approaches for distribution and implementation.

## 14. “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.

## 15. 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.

## 16. "Tribal Outreach Video –A Project of the UW Alzheimer's Disease Research Center and Partnerships for Native Health," Vimeo (2019).

- **Video Link:** <https://vimeo.com/314071595>
- **Run Time:** 5:30 minutes
- **Key Terms:** American Indian, Native Alaskan, oral tradition, memory loss, research, diversity
- **Module:** 3, 4

### Description:

The University of Washington Alzheimer's Disease Research Center seeks tribal participation to help understand the prevalence of Alzheimer's among the many Native communities.

## 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.

## Module 4: Dementia Capable Systems and Dementia Friendly Communities

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

### Guest Speakers

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

Examples of guest speakers include:

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

### Test Your Knowledge

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