A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS

MODULE 4:

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

alzheimer's association

CDC Centers for Disease Control and Prevention

Emory Rollins School of Public Health

Emory Centers for Training and Technical Assistance

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ABOUT MODULE 4

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

Module 4: Dementia Capable Systems and Dementia Friendly Communities addresses the public health response to the Alzheimer's disease epidemic at the state and community levels. The module describes the concept of a "dementia capable" system, which involves accommodating the needs of a population that experiences memory loss, a variety of **physical**, **cognitive**, and **behavior** symptoms, and other **co-morbidities**.

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

Module 4 contains the following topics:

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

LEARNING OBJECTIVES

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

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

COMPETENCIES

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

Association of Schools and Programs of Public Health:

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

Council on Linkages Between Academia and Public Health Practice:

- 1A1. Describes factors affecting the health of a community (e.g., equity, income, education, environment)
- 1A11. Describes assets and resources that can be used for improving the health of a community (e.g., Boys & Girls Clubs, public libraries, hospitals, faith-based organizations, academic institutions, federal grants, fellowship programs)
- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence and innovation)
- 8A6. Describes needs for professional development (e.g., training, mentoring, peer advising, coaching)

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Articulate evidence-based approaches to chronic disease prevention and control.

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

- 1.7.4 Identify emerging health education needs.
- 3.3.2 Identify training needs.

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

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

STUDENT ENGAGEMENT OPTIONS

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

DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

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

LEARNING ACTIVITIES

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

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

and their caregivers at home and in the community. Provide a brief description of the program, including any challenges or gaps (that are identified or that you recognize). How could public health support the expansion or improvement of this program? Document may be accessed from website: http://www.agingresearch.org/publications/view/18#.VgFoUuvL6M4

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

ADDITIONAL READING

- Bynum, Julie PW. "The long reach of Alzheimer's disease: Patients, practice, and policy." Health Affairs 33.4 (2014): 534-540. http://content.healthaffairs.org/content/33/4/534.short

- Lin, S. Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future. The Gerontologist, 55(2), 237-244. http://gerontologist.oxfordjournals.org/content/55/2/237.short

SLIDE GUIDE

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

SLIDE 1:

Module 4: Dementia Capable Systems and Dementia Friendly Communities

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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:

Learning Objectives

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

TALKING POINTS:

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

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

SLIDE 3:

Competencies

Association of Schools and Programs of Public Health:

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

Council on Linkages Between Academia and Public Health Practice:

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

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

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

Association of Schools and Programs of Public Health:

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

Council on Linkages Between Academia and Public Health Practice:

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

SLIDE 4:

Competencies Cont.

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

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

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Articulate evidence-based approaches to chronic disease prevention and control

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

- 1.7.4 Identify emerging health education needs.
- 3.3.2 Identify training needs

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

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

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

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Articulate evidence-based approaches to chronic disease prevention and control

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

- 1.7.4 Identify emerging health education needs
- 3.3.2 Identify training needs

SLIDE 5:

Introduction: Dementia & Alzheimer's Disease[1]

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

TALKING POINTS:

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

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

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

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

Alzheimer's disease is the most common type of dementia. Alzheimer's is a progressive disease that ranges from mild to severe cognitive impairment that occurs over the course of several years. There is **no cure** for Alzheimer's. While there are approved drug **treatments**, the goal of treatment is to delay or reduce symptoms, not to cure or reverse the course of the disease.

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

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

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

Video supplements: "What is Alzheimer's disease?" TedEd. (run time: 3:49 mins)
Link: https://www.youtube.com/watch?v=yJXTXN4xrI8

Or, "Inside the Brain: Unraveling the Mystery of Alzheimer Disease". National Institutes of Health, NIH Senior Health. (run time: 4 mins.)
http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a2_na.html?intro=yes

SLIDE 6:

Alzheimer's: A Larger Context[2]

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

TALKING POINTS:

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

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

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

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

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

[2] *Image source: clker.com*

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

SLIDE 7:

Dementia Capable Systems[3,4,5]

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

TALKING POINTS:

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

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

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

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

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

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

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

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

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

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

SLIDE 8:

Dementia Capable: Public Health[6]

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

TALKING POINTS:

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

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

Each of these will be discussed in more detail.

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

SLIDE 9:

PUBLIC HEALTH RESEARCH

TALKING POINTS:

We will start with public health research.

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

SLIDE 10:

Discussion Questions

What is public health research?

What does it mean to translate findings?

TALKING POINTS:

Ask: What is public health research?

What does it mean to translate findings?

Open responses.

SLIDE 11:

Public Health Research & Translation[7]

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

TALKING POINTS:

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

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

Sources for public health research and translation include:

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

[7] *Image source:* clker.com

SLIDE 12:

Discussion Question

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

TALKING POINTS:

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

Open responses.

SLIDE 13:

Public Health Research & Translation[8,9]

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

TALKING POINTS:

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

- Measuring the **burden** of cognitive impairment on populations
- Creating state and local **policies** that benefit and support people with Alzheimer's disease and their caregivers
- Identifying and designing effective **practices** and **interventions** to support the needs of individuals and their caregivers
- Promoting **risk reduction** and **cognitive health**

[8] Centers for Disease Control and Prevention. (2010) *Distinguishing Public Health Research and Public Health Nonresearch*.

[9] CDC & Alzheimer's Association. (2013) *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018.*

Image source: clker.com

SLIDE 14:

SUPPORT SERVICES & PROGRAMS

TALKING POINTS:

Public health research may be used to inform the design of **support services and programs** for people with Alzheimer's and other dementias.

SLIDE 15:

Discussion Question

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

TALKING POINTS:

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

Open responses.

SLIDE 16:

Support Services: Alzheimer's[10,11]

- Support groups
- Wellness programs
- Care services
- Legal, financial services
- Residential care
- Transportation
- Adult day care

TALKING POINTS:

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

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

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[10] U.S. Administration on Aging. (2011) *Dementia Capability Toolkit*.

[11] ACT on Alzheimer's. *Dementia Capable Community: Key Elements & Resources*. Accessed August 4, 2015 from website: http://www.actonalz.org/elements-and-resources

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

- **Care services**: includes care managers, chore services, home safety, personal care assistant
- **Legal** or **financial services**: financial, health care, and end-of-life planning
- **Residential care**: includes living options with varying levels of care, such as independent living communities, assisted living residences, and nursing homes tailored to people with dementia
- **Transportation**: includes safe driving supports and individual and group transportation options
- **Adult day care**: care for individuals who require regular supervision: allowing people to socialize, participate in activities, and provide opportunities for caregivers to work or fulfill other responsibilities

SLIDE 17:

Support Services: Caregivers[12]

- Education/information/training
  - Alzheimer's/dementia
  - Behavioral management
  - Available resources
  - Self-care
- Counseling/support groups
- Case management
- Respite services

TALKING POINTS:

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

- **Education/information/training**:
  - Alzheimer's and dementia and its effects on behavior
  - **Behavioral management/problem solving training**: designed to train caregivers to use specific techniques to manage behaviors that can be challenging (such as agitation, repetition, aggression, wandering)
  - Information on the availability of **resources**
  - Self-care, such as stress management, using respite services
- **Counseling/support groups**:
  - Individual and family **counseling**

[12] ACT on Alzheimer's. (2014). *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

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

    - **Support groups** that have been found to have the most positive outcomes focus on specific objectives, such as teaching certain skills or strategies

- **Care management**: helping to identify and manage care needs, coordinate across care systems and providers
- **Respite services**: provides care for a person with Alzheimer's disease on a temporary basis, providing time off for a family caregiver

SLIDE 18:

Examples of Evidence-based Programs[13]

- Reducing Disability in Alzheimer's Disease (RDAD) – University of Washington
  - Focus on teaching family caregivers strategies
- Minds in Motion (MIM)
  - Focus on improving function in early stages with mild cognitive impairment
- Skills2Care – Thomas Jefferson University
  - Focus on occupational therapy based strategies for caregivers

TALKING POINTS:

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

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

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

- **Minds in Motion (MIM)**: MIM is designed to improve or sustain cognitive and physical functioning in persons with mild (early) stage dementia or mild cognitive impairment (MCI). The group-based program,

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

delivered in community settings, includes a variety of evidence-based components, including:

- Cognitive training exercises
- Physical exercises (Tai Chi and Qi Gong)
- Creative/community involvement activities (writing, art, photography, etc.)

- **Skills2Care**: An occupational therapy based intervention for caregivers and individuals with dementia living at home. The intervention is designed to reduce caregiver burden, improve caregiver ability to manage daily care challenges, and reduce behavioral symptoms and functional dependence in individuals with dementia. Caregivers are trained in five types of strategies:
  - Communication techniques
  - Environmental modification
  - Task simplification
  - Use of activities to engage individuals with dementia
  - Self-care

SLIDE 19:

Discussion Question

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

TALKING POINTS:

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

Open responses.

SLIDE 20:

Public Health: Support Services[14]

- Evidence-based programs and interventions
- Information and referrals
- Identifying service needs
- Funding, space, expertise

TALKING POINTS:

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

Public health agencies and organizations can:

- **Develop** and **disseminate** evidence-based programs and interventions
- Offer **Information** and **referrals** to specific support services, programs, and sources of information
- Assist in **identifying service needs**, helping people understand what is available and how they may use different services throughout the course of the disease
- **Provide funding**, **space**, **expertise**, or other support for needed programs

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

SLIDE 21:

Support Services: Partnerships[15]

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

TALKING POINTS:

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

- **Offices on Aging/Aging and Disability Resource Centers/Area Agencies on Aging** can partner with local public health departments to **assess** community needs, **develop** programs and supports, and **provide** referrals.

  Staff may be knowledgeable about Alzheimer's and dementia, offer **cognitive assessments** and family **caregiver supports**, and have information about **resources** and **programs** available in the community for individuals with dementia and their families.

- **Non-profit organizations** such as the **Alzheimer's Association** have experts in the field of dementia care with a wide variety of information and educational

[15] ACT on Alzheimer's. (2014). *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

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

materials and programs to support individuals, families and caregivers.

Other non-profits, such as **faith-based organizations** and **civic groups**, can be partners that may co-sponsor educational events, distribute information, offer services, provide a place for caregiver support groups to meet, etc.

- **Residential care facilities** may be able to reach out to other health care and business partners in the community to promote awareness, support program development, and initiate dementia friendly policies.

SLIDE 22:

WORKFORCE TRAINING

TALKING POINTS:

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

SLIDE 23:

Workforce Training[16]

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

TALKING POINTS:

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

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

Each of these will be discussed in more detail.

[16] *Image source:* Centers for Disease Control and Prevention, Debora Cartagena (Photographer)

SLIDE 24:

Discussion Question

What training should health care and direct care professionals receive?

TALKING POINTS:

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

Open responses.

SLIDE 25:

Workforce Training: Health Care & Direct Care[17]

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

TALKING POINTS:

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

- The basics of **dementia**, including recognizing early warning signs
- The benefits of **early diagnosis**
- How to address the physical, cognitive, emotional, and behavioral **symptoms** of the disease
- How to assist **caregivers** as they cope with the physical and emotional aspects of their caregiving responsibilities
- Management of **co-morbidities** (such as arthritis, diabetes, and heart disease)
- The availability and use of **tools** and **guidelines** to identify dementia, including validated cognitive assessment tools (health care providers)

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

SLIDE 26:

Discussion Question

What training should public health professionals receive?

TALKING POINTS:

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

Open responses.

SLIDE 27:

Workforce Training: Public Health[18]

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

TALKING POINTS:

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

Training and education priorities for public health include:

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

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

SLIDE 28:

Discussion Question

What training should first responders receive?

TALKING POINTS:

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

Open responses.

SLIDE 29:

Workforce Training: First Responders[19]

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

TALKING POINTS:

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

- **Wandering**, being **lost** or **disoriented**
- **Natural** or **other disasters** that may displace individuals with Alzheimer's and/or separate them from their usual caregivers
- Being subjected to physical or financial **abuse**
- Being reported to law enforcement for **improper behavior**, such as leaving a place of business after forgetting to pay for purchase

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

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

[19] *Image source:* Wikimedia commons, Jeshua Nace (photographer)

- Existence of **special needs registries** or other technologies that may assist in locating individuals or their places of residence

SLIDE 30:

Workforce Training: Other Professions[20]

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

TALKING POINTS:

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

- **Public transportation**: For individuals with dementia, navigating public transportation can be very challenging.

  Operators and drivers need to be aware of the special challenges faced by individuals with dementia, as well as how to recognize the signs that someone may need help.

- **Customer service:** Those in service positions may be trained to recognize when they are dealing with someone with possible Alzheimer's and dementia and how to best communicate with them and meet their needs.

- **Faith or spiritual communities:** These communities can be an important source of support and engagement for people with dementia, their families, and their caregivers. Church liaisons and volunteers may be trained to assist and support community members living with dementia.

[20] *Image source:* Pedestrian and Bicycle Information Center, Dan Burden (Photographer)

SLIDE 31:

DEMENTIA FRIENDLY COMMUNITIES

TALKING POINTS:

Many of the issues discussed in this module tie into the concept of **dementia friendly communities.**

This is growing movement in which communities in the U.S. and around the world are intentionally making changes to ensure that their communities are not only safe for and accessible to people with Alzheimer's and dementia, but also that they can support and empower people with Alzheimer's and dementia to continue living high-quality lives with as much independence as possible.

SLIDE 32:

Discussion Questions

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

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

How could those be addressed at a community level?

TALKING POINTS:

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

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

How could those be addressed at a community level?

Open responses.

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

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

SLIDE 33:

Dementia Friendly Communities[21,22]

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

TALKING POINTS:

In **dementia friendly** communities, people with dementia and their family and caregivers are understood, respected and supported, and able to continue to engage with and contribute to their community. The effort to become **dementia friendly** is made on a community-wide basis and requires planning and participation from all sectors as well as the general public.

While overlap exists between the concepts of dementia capable (discussed previously) and dementia friendly, a dementia-friendly community encompasses a broader goal of supporting a higher quality of life for people with dementia beyond simply meeting their physical and health needs.

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[21] U.S. Administration for Community Living/Administration on Aging. (2014) *Dementia-Capable States and Communities: The Basics.*

[22] The Gerontological Society of America. (2015) *Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future.*

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

Elements of a dementia friendly community include:

- Access to **quality health care** and **community services.** While encompassing the same aspects of dementia capable systems, dementia friendly communities offer:
    - Resources and supports that are **geographically**, **financially**, and **culturally available** and **accessible.**
    - **Support services and activities**, such as educational sessions regarding symptoms, disease processes, self-care, and providing care, as well as support groups and dementia friendly social events that are readily available throughout the community.
- **Ensure safety and accessibility**: People can live **safely**, with as much independence as possible.

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

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

people navigate their community while still allowing family or caregivers to track their whereabouts.

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

  The registry provides the name, home address, and contact information for family members or care partners should the individual with dementia need help or become involved with law enforcement.

International community models differ slightly from those in the U.S. in that internationally, a more holistic approach is often taken, while in the U.S., communities lean more on a practical and structural approach, gradually ensuring all systems and services within the community are designed to support members living with dementia and their care partners. In the following slides, we will look at some examples of communities and organizations working to become dementia friendly.

SLIDE 34:

Dementia Friendly Communities[23]

- Infographic of dementia friendly communities

TALKING POINTS:

ACT on Alzheimer's is a state-wide collaboration in Minnesota. We will learn more about the organization a few slides later. Here is an infographic that illustrates ACT on Alzheimer's view on what a dementia-friendly community involves:

- Raising awareness about Alzheimer's, transforming attitudes, and moving people to action
- Supporting family and friend caregivers by providing accessible information, resources, and in-person support
- Promoting meaningful participation in community life for everyone
- Including communities that experience inequities because of race, ethnicity, culture, language, sexual orientation, gender identity, mental illness, hearing/sensory differences, intellectual or physical abilities, and economic status

[23] *Image source:* ACT on Alzheimer's® developed tools and resources. http://actonalz.org/

SLIDE 35:

Dementia Friendly: Middleton, WI[24,25]

- Business trainings
- Business promotions
- Memory trail/park
- Evaluation criteria

TALKING POINTS:

The **Alzheimer's & Dementia Alliance of Wisconsin (ADAW)** started a pilot dementia friendly program in Middleton, Wisconsin, in January 2014.

They brought together a group of citizens, business members, and city staff to launch the program, where they developed guidelines for businesses and organization to meet in order to be designated "dementia friendly":

- Complete DFC training for management and 50% of their front-line employees
- Designate a team leader to be liaison between their organization and the DFC task force
- Be open to discussions regarding environment changes (e.g. lighting, signage, layout, etc.)
- Be willing to share DFC training materials with any new hires and all employees that did not attend training
- Undergo an on-site visit/follow-up training on an annual basis to recertify its dementia friendly status

[24] Wisconsin Department of Health Services. *Wisconsin Healthy Brain Initiative, A Tool Kit for Developing Dementia-Friendly Communities*.

[25] Alzheimer's and Dementia Alliance of Wisconsin. Dementia Friendly Community. http://www.alzwisc.org/Dementia%20Friendly.html.

Image source: ADAW

Dementia friendly organizations are given a window decal depicting a purple angel to display, allowing residents to easily identify participating locations. All city management departments are involved in the effort, including first responders. Middleton's local library, one establishment that has taken the steps to become designated dementia friendly, offers dementia-focused community programs such as a Music and Memory class. The local Walgreens also earned the dementia-friendly label and has improved signage throughout their stores as well as trained their employees on how to interact successfully with their customers with dementia. Banks, restaurants, local shops, and groceries are also trained.

ADAW is looking forward to expanding their dementia friendly training to personal service providers, such as beauticians and barbers, and even dentists. They are now working with other communities in Wisconsin to support them as they become dementia friendly.

Visit: http://www.alzwisc.org/Dementia%20Friendly.html for more information

SLIDE 36:

Dementia Friendly: ACT on Alzheimer's[26]

- Minnesota's statewide, volunteer-driven collaboration
- Community toolkit
  - Form action team
  - Assess community strengths and gaps
  - Analyze needs and develop action plan
  - Pursue priority goals

TALKING POINTS:

ACT on Alzheimer's is a statewide, volunteer-driven collaboration in Minnesota focused on preparing communities to respond to the growth of their populations with Alzheimer's and dementia. The goal is to create a community that raises awareness about Alzheimer's, transforms attitudes, and moves people to action; supports family and friend caregivers by providing accessible information, resources, and in-person support; promotes meaningful participation in community life for everyone; and includes communities that experience inequities because of race, ethnicity, culture, language, sexual orientation, gender identity, mental illness, hearing/sensory differences, intellectual or physical abilities, and economic status. Currently, 35 communities across the state participate in the initiative.

The process follows four action phases:

Convene key community leaders and members to form an **action team**

Assess **strengths** and **gaps** within the community related to dementia-friendly aspects

Analyze community needs and develop **action plans** to respond

1. **Launch** action plans

[26] ACT on Alzheimer's. (2013). *Is Your Community Prepared?*

Image source: ACT on Alzheimer's

ACT on Alzheimer's released a **toolkit** that is available for use by communities to create dementia-friendly environments. The toolkit includes sector specific training guides, such as those targeted toward businesses, finance, legal, and local government entities. Additionally, ACT offers a "Dementia Friendly @ Work" in-person training session to teach businesses and organizations about dementia and how they can take action to create an environment that is safe, respectful and welcoming for those with dementia. Those who complete the training are given posters, media materials and window stickers recognizing them as "dementia friendly."

Visit: http://actonalz.org/ for more information

SLIDE 37:

Dementia Friendly America (DFA)[27]

- Raising awareness about dementia
- Having supportive options that foster quality of life
- Supporting caregivers and families
- Meaningful participation in community life
- Reaching the underserved

TALKING POINTS:

The **Dementia Friendly America (DFA)** initiative is a national effort to equip all sectors of the community to support people with dementia and their caregivers and family.

The focus of DFA includes:

- Raising awareness about dementia and transforming attitudes and understanding of the conditions
- Having supportive options that foster quality of life on a community level
- Supporting caregivers and families
- Promoting meaningful participation in the community by people with dementia and their caregivers
- Reaching those in the community who are underserved

DFA is modeled after the community process developed by Minnesota's ACT on Alzheimer's. They provide a "Dementia Friendly Toolkit", sector specific guides, healthcare provider practice tools, and training videos for their partner communities to utilize as those communities work to become dementia-friendly. In 2015, 7 communities launched DFA's

[27] Dementia Friendly America press release, *Dementia Friendly America Initiative Launches in Communities Across the U.S., from Maryland to California*, July 13, 2015.

Image source: Dementia Friendly America

initiative, and another 80 communities across 30 states are looking to join them in 2016.

Visit: http://www.dfamerica.org for more information

SLIDE 38:

Dementia Friendly Tempe[28]

- Arizona's first dementia friendly city
- Formed Action Team led by Chamber of Commerce
- Weekly Memory Café at library where people with dementia and caregivers can meet others
- "Dementia Friends" training to educate community on how to support dementia friendly efforts

Dementia Friendly Tempe (DFT), an initiative utilizing the Dementia Friendly America framework, is Arizona's first dementia-friendly city. The effort was initiated in 2015 by Tempe's mayor, Mark Mitchell, after his mother was diagnosed with Alzheimer's, and has since gained community-wide and legislative support. While still in the planning stages, Tempe has made significant progress:

- Held a successful kickoff summit in the community (see YouTube video below)
- Held Action Team meetings led by the Chamber of Commerce, where they are reviewing results of a survey given to sectors across the community to assess needs. Once the data review is completed, the Action Team will develop a strategic plan. Additionally, the Action Team is expecting to conduct environmental assessments of public spaces.

[28] Dementia Friendly America press release, *Dementia Friendly America Initiative Launches in Communities Across the U.S., from Maryland to California*, July 13, 2015.

Image source: dementiafriendlytempe.org

- Hired a coordinator for the DFT initiative to be housed in City Hall to more closely align with the Mayor's office.
- Launching a weekly Memory Café at the Tempe Library, where people with dementia and their care partners can meet others in the community in like situations. The Café will be staffed by a professional who can answer questions, provide/direct access to resources and learn what participants hope to get from attending. Additionally, a monthly arts engagement program will be offered within the Café setting. The City of Tempe is handling the promotion of the event.
- Holding monthly community lectures at the Tempe Library that will include a variety of topics regarding dementia.
- Planning to launch "Dementia Friends" training to educate community members on how they can contribute to the dementia friendly efforts.

Visit http://www.dementiafriendlytempe.org for more information

Video supplement: Video highlighting Tempe's Initiative
(5:06 minutes)
https://www.youtube.com/watch?v=3zJOFQaUBAY

SLIDE 39:

Conclusion: Dementia Capable and Dementia Friendly[29]

- States/communities play significant role
- Dementia capable systems
    - Public health research and translation
    - Support services and programs
    - Workforce training
- Dementia friendly communities

TALKING POINTS:

In conclusion, let's review the key points from this presentation. States and communities play an active role in reducing the burden of the Alzheimer's and dementia epidemic. Two approaches are by creating **dementia capable systems** and **dementia friendly communities**. The concepts are similar and can overlap, but the focus of both is on accommodating those with dementia and their caregivers through providing support and services within their communities.

Public health must take an active role in fostering dementia capable systems and dementia friendly communities through:

- Conducting **public health research** on the burden of Alzheimer's and dementia, and use findings to design effective programs, policies, and best practices
- Serving to provide, inform and connect individuals and caregivers to **support services and programs**
- Designing and implementing **workforce training** to ensure workers across a wide range of professions are able to identify and meet the needs of people with Alzheimer's and dementia

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

- Supporting the creation of **dementia friendly communities** that help people with Alzheimer's and dementia remain safe and as independent as possible

SLIDE 40:

For More Information

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

TALKING POINTS:

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

A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

alzheimer's association

CDC Centers for Disease Control and Prevention

EMORY ROLLINS SCHOOL OF PUBLIC HEALTH | Emory Centers for Training and Technical Assistance

LEARNING OBJECTIVES

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

2

COMPETENCIES

Association of Schools and Programs of Public Health:

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

Council on Linkages Between Academia and Public Health Practice:

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

3

COMPETENCIES CONT.

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

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

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Articulate evidence-based approaches to chronic disease prevention and control.

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

- 1.7.4 Identify emerging health education needs.
- 3.3.2 Identify training needs.

4

INTRODUCTION: DEMENTIA & ALZHEIMER'S DISEASE

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

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

ALZHEIMER'S: A LARGER CONTEXT

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

6

DEMENTIA CAPABLE SYSTEMS

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

[3] Alzheimer's Association and Centers for Disease Control and Prevention. (2013) The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018.
[4] U.S. Administration on Aging. (2011) Dementia Capability Toolkit.
[5] Tilly, J, Weiner, J, Gould, E, and O'Keefe, J. (2011) Making the Long-Term Services and Supports System Work for People with Dementia and Their Caregivers.

7

DEMENTIA CAPABLE: PUBLIC HEALTH

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

8

PUBLIC HEALTH RESEARCH

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

9

DISCUSSION QUESTION

What is public health research?
What does it mean to translate findings?

10

PUBLIC HEALTH RESEARCH & TRANSLATION

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

11

DISCUSSION QUESTION

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

12

PUBLIC HEALTH RESEARCH & TRANSLATION

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

[8] Centers for Disease Control and Prevention. (2010) *Distinguishing Public Health Research and Public Health Nonresearch*.
[9] CDC & Alzheimer's Association. (2013) *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018.*

13

SUPPORT SERVICES & PROGRAMS

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

14

DISCUSSION QUESTION

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

15

SUPPORT SERVICES: ALZHEIMER'S

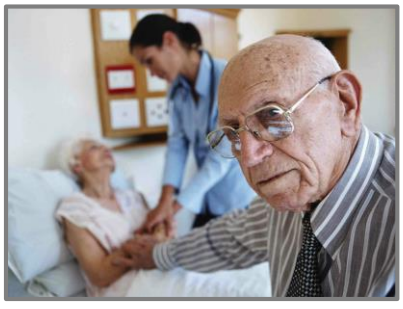
- Support groups
- Wellness programs
- Care services
- Legal, financial services
- Residential care
- Transportation
- Adult day care

16

[10] U.S. Administration on Aging. (2011) *Dementia Capability Toolkit*.
[11] ACT on Alzheimer's. *Dementia Capable Community: Key Elements & Resources*. Accessed August 4, 2015 from website: http://www.actonalz.org/elements-and-resources

SUPPORT SERVICES: CAREGIVERS

- Education/information/training
  - Alzheimer's/dementia
  - Behavioral management
  - Available resources
  - Self-care
- Counseling/support groups
- Care management
- Respite services



17

[12] ACT on Alzheimer's. (2014). *Alzheimer's Disease Curriculum, Module X: Caregiver Support.*

EVIDENCE-BASED PRACTICE

- Reducing Disability in Alzheimer's Disease (RDAD) – University of Washington
  - Focus on teaching family caregivers strategies
- Minds in Motion (MIM)
  - Focus on improving function in early stages with mild cognitive impairment
- Skills2Care – Thomas Jefferson University
  - Focus on occupational therapy based strategies for caregivers

18

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

DISCUSSION QUESTION

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

19

SUPPORT SERVICES: PUBLIC HEALTH

- Evidence-based programs and interventions
- Information and referrals
- Identifying service needs
- Funding, space, expertise

20

SUPPORT SERVICES: PARTNERSHIPS

- Offices on Aging / Aging and Disability Resource Ce
  Agencies on Aging
  - Education
  - Cognitive assessments
  - Support programs
  - Resources
- Non-profit organizations
- Residential care facilities

[15] ACT on Alzheimer's. (2014). *Alzheimer's Disease Curriculum, Module X: Caregiver Support.*

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WORKFORCE TRAINING

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

22

WORKFORCE TRAINING

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

23

DISCUSSION QUESTION

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

24

WORKFORCE TRAINING: HEALTH CARE & DIRECT CARE

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

25

DISCUSSION QUESTION

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

26

WORKFORCE TRAINING: PUBLIC HEALTH

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

Public Health
Prevent. Promote. Protect.

27

DISCUSSION QUESTION

What training should **first responders** receive?

28

WORKFORCE TRAINING: FIRST RESPONDERS

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

29

WORKFORCE TRAINING: OTHER PROFESSIONS

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

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DEMENTIA FRIENDLY COMMUNITIES

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

31

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?

32

DEMENTIA FRIENDLY COMMUNITIES

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

[21] U.S. Administration for Community Living/Administration on Aging. (2014) *Dementia-Capable States and Communities: The Basics.*
[22] The Gerontological Society of America. (2015) *Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future.*

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DEMENTIA FRIENDLY COMMUNITIES

34

Reproduced from ACT on Alzheimer's® developed tools and resources.

DEMENTIA FRIENDLY: MIDDLETON, WI

- Business trainings
- Business promotions
- Memory trail/park
- Evaluation criteria

[24] Wisconsin Healthy Brain Initiative. *A Tool Kit for Building Dementia-Friendly Communities*
[25] Alzheimer's and Dementia Alliance of Wisconsin. Dementia Friendly Community. http://www.alzwisc.org/Dementia%20Friendly.html

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DEMENTIA FRIENDLY: ACT ON ALZHEIMER'S

- Minnesota's statewide, volunteer-driven collaboration
- Community toolkit
  - Form action team
  - Assess community strengths and gaps
  - Analyze needs and develop action plan
  - Pursue priority goals

ACT ON ALZHEIMER'S

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[26] ACT on Alzheimer's. (2013). *Is Your Community Prepared?*

DEMENTIA FRIENDLY AMERICA (DFA)

- Raising awareness about dementia
- Supportive options that foster quality of life
- Supporting caregivers and families
- Meaningful participation in community life
- Reaching the underserved

Dementia Friendly America®

[27] Dementia Friendly America press release, *Dementia Friendly America Initiative Launches in Communities Across the U.S., from Maryland to California*, July 13, 2015.

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DEMENTIA FRIENDLY TEMPE

- Arizona's first dementia friendly city
- Formed Action Team led by Chamber of Commerce
- Weekly Memory Café at library where people with dementia and caregivers can meet others
- "Dementia Friendly" training to educate community on how to support dementia friendly efforts

[28] Dementia Friendly America press release, *Dementia Friendly America Initiative Launches in Communities Across the U.S., from Maryland to California*, July 13, 2015.

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CONCLUSION: DEMENTIA CAPABLE AND DEMENTIA FRIENDLY

- States/communities play significant role
- Dementia capable systems
  - Public health research and translation
  - Support services and programs
  - Workforce training
- Dementia friendly communities

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FOR MORE INFORMATION

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

alzheimer's association

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SAMPLE TEST QUESTIONS

1- Which professions need to be knowledgeable about dementia?

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

Answer: E

2- Research translation is best described as:

a. Making research available in different languages
b. Putting research findings into practice
c. Developing new methods for conducting research
d. Using plain language to explain research findings

Answer: B

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

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

Answer: E

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

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

Answer: A

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

a. True
b. False

Answer: A

Selected Case Studies- Module 4

On the suggested video resources list, there are several well done documentaries that cover various aspects of Alzheimer's and its impacts on individuals and families. Several of the suggested videos are used as case studies with discussion questions that can be used in class or as an outside assignment.

The case studies are designed to be used in conjunction with the article or video listed. The program title, run time, web link, keywords, relevance to modules, a program description and discussion questions are listed for each piece.

It is recommended that the audio/video be used in conjunction with the discussion questions. However, if time and/or internet access is limited, each case study has a summary that provides enough information to generate discussion or conversation without having to view the video.

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

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

Description:

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

Once in Los Angeles, Mrs. Williams' memory problems grew increasingly worse. Mrs. Williams began wandering and becoming lost. During moments of lucidity, Mrs. Williams begged her daughter to return her to her home on the reservation. Eventually Delma and her family moved back to the reservation. Mrs. Williams has thirteen other children who lived in that area, but Delma is the only one who cares for their mother. Delma is not sure why her siblings do not visit their mother and their absence upsets her. Delma also feels guilty for doubting her mother when she first mentioned having memory issues.

Discussion Questions:

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

2- "Inside Alzheimer's: What's it like to live with early-onset Alzheimer's disease? Greg O'Brien offers a glimpse," NPR special series (2015).

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

Description:

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

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

Mary Catherine says that Alzheimer's disease changed Greg's personality in many ways. On one hand, Greg discusses certain topics with her more openly than he would have in the past, but she also has noticed that he gets angry now, something he never used to do before. In the past, Greg was a loud, outgoing man who was often was at the center

of discussion. Now he is quieter and more solitary, even disappearing into a different room when crowds of visitors become overwhelming for him. Greg also used to run upwards of six miles daily as a part of his daily routine; however, he began getting lost and switched to running in a gym.

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

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

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

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

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

Discussion Questions:

- Why is it important that individuals with Alzheimer's disease are diagnosed early?
    - When individuals are exhibiting signs of Alzheimer's disease, the people around them need to understand what is happening so they can be patient and react in an understanding way.

    - Being able to make important decisions about their care, including at the end of life, and finances while they are still able to make informed decisions.
- What are ways that Greg can maintain his independence as his Alzheimer's disease progresses?
    - Going to the gym worries his family in case he gets lost on the way. A GPS app on his phone can alert his family to his location.
- Discuss the importance of end of life planning and role of public health in encouraging people to make plans.
- Discuss the importance of a strong social network and family support.
    - In one of the interviews, Greg talks about how where he lives is a small town where everyone knows everyone and their business. As word of his Alzheimer's disease spread and more people in his town knew about it, people eventually began introducing themselves to him when they began a conversation in order to help him identify them.
- Discuss the advantages and disadvantages of deciding not to treat stage-three prostate cancer as Alzheimer's disease progresses.

3- "Can Technology Ease the Burden of Caring for People with Dementia?" NPR (2015).

- **Audio/Transcript Link:** http://www.npr.org/templates/transcript/transcript.php?storyId=417205451
- **Run Time:** 4:35 minutes (audio)
- **Key Terms:** care givers burden, financial burden, healthcare system, family support, technology, monitoring systems, long term care
- **Modules:** 1, 2, 3, **4**

Description:

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

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

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

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

Discussion Questions:

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

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

- **Video Link:** http://myuctv.tv/2012/09/18/alzheimers-the-long-and-costly-goodbye/
- **Run Time:** 12:30 minutes
- **Key Terms:** stigma, loss of identity, increasing prevalence, increasing aging population, caregiver's burden, family relationships, financial burden
- **Modules:** 1, 2, 3, **4**

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

Case Study: Patti

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

Patti planned on leaving an inheritance for her son when she passed away. Patti has a reverse mortgage, which is a special type of home loan for older adults that allows them to convert a portion of the equity of the home into cash. Older adults often use the cash

payments to supplement income from Social Security, for unexpected medical expenses, home improvements, and many other uses. Alzheimer's disease is a costly disease. Patti now worries that she will no longer be able to leave an inheritance for her son because she could be drained of all her finances to cover her care needs.

Discussion Questions:

- Consider the costs that are associated with medical care and long-term services for people with dementia. What kinds of financial protections are in place to protect older adults' finances who live on a fixed income?
- What are other countries doing to provide quality and affordable medical care to their older adults?
- How does financial planning play a role in preparing for aging, potential onset of illnesses or disability, and the associated costs of care?

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

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

Description:

This documentary shares the stories of five caregivers and demonstrates the struggle and resilience of the caregiver when a family member is diagnosed with Alzheimer's disease. These caregivers struggle to balance their own lives and responsibilities with the daily duties and responsibilities of caring for a loved one with Alzheimer's disease. This documentary illustrates the many challenges and sacrifices, such as personal responsibilities as well as social stigma that caregivers go through in order to care for their loved ones in the family home as well as in nursing care facilities.

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

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

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

Marianne is Chuck's ex-wife. After Chuck's diagnosis, Marianne invited Chuck back and became his primary caregiver. As the caregiver, it is important for Marianne to maintain

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

Discussion Question:

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

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

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

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

Discussion Questions:

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

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

Mike has six brothers and sisters and runs his own business; he is also the primary caregiver for his father, Nacho, who has Alzheimer's disease. Mike is the primary caregiver for his father because he had extra space in his house. A year and half into Nacho living with Mike, Mike's girlfriend moved out due to the enormous amount of

stress that caring for Nacho put on their relationship. Mike feels similar stress in his other relationships with family and friends. There are many ups and downs that come with taking care of Nacho. Mike and the adult day center where Nacho spends days adjust games in small ways that allow Nacho to win. It is important to help Nacho retain self-worth as his Alzheimer's becomes increasingly degenerative. Without self-worth, depression overtakes Nacho. Sometimes Mike feels as if he can provide in-home primary care for his father for months, years, even decades, but then his father has another Alzheimer's disease-related issue bringing back the reality of Alzheimer's disease.

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

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

Discussion Questions:

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

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

When they were first married, Marvine and Jackie vowed to never put each other in nursing homes. Eventually, Marvine was diagnosed with Alzheimer's disease and Jackie began having health issues. Jackie felt like she did not have a choice about moving Marvine to a nursing home and this was a very difficult decision for her. Marvine has

been living in the nursing home for a few years now and Jackie visits him often. Jackie tends to dress very nicely and carefully when she visits her husband because on the days he does remember her, this makes him very happy. While visiting her husband, she feeds him because this is one of the few ways that she can provide care for him.

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

Discussion Questions:

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

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

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

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

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

Discussion Questions:

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

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

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

Description:

"The Memory Loss Tapes" are part of a four-part HBO documentary series entitled *The Alzheimer's Project*. This documentary gives a short glimpse into the lives of seven individuals in varying stages of Alzheimer's disease. Each of the profiles gives insight into the lives of those living with the diagnosis, their surrounding family members and caregivers, and their reactions to the diagnosis. Central themes in this documentary include loss of independence, confusion, fear and anxiety, and the importance of support and community resources.

Case Studies:

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

Bessie is an 87 year old woman who was diagnosed with Alzheimer's disease two months ago. Bessie is in the mild (early) stages of Alzheimer's disease, and she is still very independent, able to drive and live alone. Bessie is active in her community. Everyone in town knows Bessie and she is well loved. Bessie volunteers with other women to sing in nursing homes. When Bessie can't remember who people are, they remind her, but a few minutes later, she forgets who they are again. Bessie's friends have noticed her Alzheimer's disease and they worry about her. Bessie's daughter and son-in-law want her to take medications that may slow the progression of her Alzheimer's disease. Bessie has a positive perspective on life and does not believe in giving up. Her daughter attributes this positive attitude towards how well Bessie is doing. Bessie is still very intelligent and alert, but she knows she has Alzheimer's disease which is causing her memory issues. Bessie's children worry about how they will care for

her as her Alzheimer's disease progresses, when she begins forgetting she has Alzheimer's disease or no longer understands what Alzheimer's disease means.

Discussion Questions:

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

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

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

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

Discussion Questions:

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

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

Joe is 63 years old and was diagnosed with Alzheimer's disease two years ago. Joe found his passion in the 1980s working in the technology industry. He helped develop CDs and DVDs. Now, Joe writes a blog about his Alzheimer's disease diagnosis and living with the disease. Joe chronicles the struggles of his progressing Alzheimer's disease, such as

getting locked out of his house, forgetting how to get back in his house, and being afraid to leave home in case he gets lost and cannot get back. For example, one day Joe took his granddaughter to play at the park. He forgot how to get home and could not remember where he was. Fortunately, his granddaughter knew how to get home, and they returned safely. This is just one example of Joe getting lost and endangering his and others' safety.

Joe struggles with his Alzheimer's diagnosis emotionally and physically. Sometimes, Joe is so overwhelmed with forgetting peoples' faces that he no longer wants to interact with anyone. Joe also knows that he is getting worse over time and worries about "stepping over the line" and becoming a completely different person. He attends counseling to help with this anxiety and the emotional toll of Alzheimer's disease. Joe has begun end-of-life planning and is determined not to lose himself in the disease. Joe tries to reconcile his existence and meaning within the context of the universe, but finds it very difficult. It upsets his family when he talks about dying.

Discussion Questions:

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

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

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

Discussion Question:

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

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

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

Woody is an 81 year old man who was diagnosed with Alzheimer's disease 14 years ago. Woody has always loved singing, and this passion has remained with him throughout his Alzheimer's progression. Woody now lives in a nursing home, but his family takes him to sing with his old singing group often. During the trip out, Woody asks the same

questions over and over and does not know what is happening. However, while performing, Woody can still sing all the words. Woody, who has been married for many years, does not remember that he is married but recognizes his wife and daughter when they come to visit. In the nursing home, he has female admirers. The film shows Woody spending time with a female resident who is very affectionate; they hold hands, kiss and take a nap with one another.

Discussion Questions:

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

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

Josephine is a 77 year old woman who was diagnosed with Alzheimer's disease five years ago. After Josephine's diagnosis, her daughter moved from her job and life in the city to a farm where Josephine lives with her. Josephine's daughter locks the farm gates and constantly worries about Josephine getting lost on the farm. Fortunately, Josephine's daughter was able to put up a fence around the farm, which has helped her to keep track of Josephine. Josephine's daughter must constantly watch on her mother for her safety and make sure she does not get into trouble. For example, Josephine often puts things in her mouth that must be removed despite Josephine's protests. Josephine's daughter does not know how much longer she will be able to care for her mother at home on the farm.

Josephine no longer speaks, but does communicate a little through sounds such as humming. Josephine also leaves small art arrangements using small objects around the house that her daughter documents with photographs. These vignettes tell her daughter that Josephine is still there beneath her progressing Alzheimer's disease. Josephine also paints on both canvases and rocks. Unfortunately, Josephine paints white over many of her canvas paintings and these no longer exist.

Discussion Questions:

- What could be some special challenges for people in rural areas who are living with or caring for someone affected by Alzheimer's?
- How can we improve the home to ensure the safety and health of older adults with Alzheimer's disease?
- What resources are available to caregivers?

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

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

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

Discussion Questions:

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

Alzheimer's Disease Video Resources

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

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

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

Description:

This interactive tour helps explain the basic components of the brain and how Alzheimer's disease affects it. The tour teaches the participant the different parts of the brain, how Alzheimer's disease damages the brain and brain activity, and the different stages of the disease.

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

- **Video Link:** https://www.youtube.com/watch?v=yJXTXN4xrI8
- **Run Time:** 3:49 minutes
- **Key Terms:** stages of Alzheimer's, pathology of Alzheimer's
- **Modules:** 1, 2

Description:

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

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

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

Description:

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

President Ronald Reagan, and television personality Leeza Gibbons, who lost her mother to the disease.

a) **Alzheimer's Long and Costly Goodbye – Heartache & Hope: America's Alzheimer's Epidemic (Ep. 1)**
   - **Video link:** http://myuctv.tv/2012/09/18/alzheimers-the-long-and-costly-goodbye/
   - **Run time:** 12:30 minutes
   - **Key terms:** dementia, diagnosis, cost
   - **Description:** As Baby Boomers become senior citizens, Alzheimer's Disease and other forms of dementia are on track to reach epidemic proportions, with a new case every 68 seconds and an annual cost of $1.2 trillion projected by 2050. The disease also takes its toll on family members struggling to care for their loved ones, while watching them slowly slip away in what some describe as "the long goodbye." The first in a series of three programs from UCLA offers an overview of the looming epidemic and illustrates the fear and grief experienced by patients and their loved ones, including Patti Davis, daughter of Ronald Reagan, and TV personality Leeza Gibbons, who lost her mother to Alzheimer's.

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

c) **Alzheimer's Patient and Caregiver Support - Heartache & Hope: America's Alzheimer's Epidemic (Ep. 3);**
   - **Video link:** http://www.uctv.tv/shows/Alzheimers-Patient-and-Caregiver-Support-Heartache-Hope-Americas-Alzheimers-Epidemic-Ep-3-23981
   - **Run Time:** 12:26 minutes
   - **Key Terms:** caregiver support, patient support, resources

- **Description:** It's often said, "If you've seen one person with Alzheimer's, then you've seen one person with Alzheimer's." The disease affects everyone differently, but all patients and their families experience some form of grief and fear, not to mention the stress put on the caregivers. The third and final installment in this series from UCLA offers up new models for healthcare and caregiver support that emphasize early diagnosis and support networks for everyone touched by the disease, including Patti Davis, daughter of Ronald Reagan, and TV personality Leeza Gibbons, who lost her mother to Alzheimer's.

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

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

Description:

This documentary shares the stories of 5 caregivers and demonstrates the struggle and resilience of the caregiver when a family member is diagnosed with Alzheimer's disease. These caregivers struggle to balance their own lives and responsibilities with the daily duties and responsibilities of caring for a loved one with Alzheimer's disease. This documentary illustrates the many challenges and sacrifices of a caregiver, such as personal responsibilities and the social stigma of caring for a loved one whether in their family home or in professional medical facilities.

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

- **Video Link:** http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a2_na.html?intro=yes
- **Run Time:** 4:21 minutes
- **Key Terms**: neurobiology of Alzheimer's disease, the brain, cellular circuitry, cellular communication, neurotransmission, beta amyloid plaque formation, neurofibrillary tangle formation
- **Modules**: 1, 2

Description:

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

6- **"Understanding the Selfhood of People with a Dementia: Context Is Key, "** Dr. Steven Sabat and Dementia Alliance International (2015).

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

Description:

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

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

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

Description:

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

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

- **Video Link:** http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a6_na_intro.html

- **Run Time:** 2:29 minutes
- **Key Terms:** biology and behavioral changes of Alzheimer's disease
- **Modules:** 1, 2

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

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

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

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

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

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

Description:
This film tells five stories of children, ages 6-15, who are coping with grandfathers or grandmothers suffering from Alzheimer's disease. Maria Shriver provides commentary and delivers valuable "lessons" for the kids, urging them not to blame themselves for what their grandparents do or say. "We are all children of Alzheimer's," says Shriver, sympathetically making it clear that "if it's too painful to visit, you don't have to go." Maria's own father, Sargent Shriver, suffers from the

disease; comparing his earlier vitality to his present condition is hard, but it is offset by good memories and an unexpected "gift": bonds between generations that may not have been made otherwise. Ultimately, the film shows how important it is to "go with the flow," offering up a variety of perspectives on how kids can handle a grandparent's loss of memory through kindness, patience, and compassion.

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

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

Description:

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

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

b) **"How Far We Have Come in Alzheimer's Research"**
   - **Run Time:** 15:18 minutes
   - **Key Terms:** treatment, research
   - **Description:** This clip discusses the rapid progress in Alzheimer's development and treatment research.

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

d) **"The Role of Genetics in Alzheimer's"**
   - **Run Time:** 14:18 minutes

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

e) "Advances in Brain Imaging"

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

f) "Looking into the Future of Alzheimer's"

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

g) "The Connection Between Insulin and Alzheimer's"

- **Run Time:** 21:50 minutes
- **Key Terms:** insulin resistance, insulin resistance as a risk factor, research, treatment, fat, diet, beta amyloid plaque accumulation and high saturated fat intake, insulin and memory, hippocampus, frontal lobe, intranasal insulin treatment
- **Description:** This researcher discusses the evidence that insulin resistance (diabetes) may contribute to developing Alzheimer's disease through diet and insulin levels in the brain.

h) "Inflammation, the Immune System, and Alzheimer's"

- **Run Time:** 29:23 minutes
- **Key Terms:** inflammation in the brain, brain samples, brain cells as living targets, vaccines, mouse models, microglia
- **Description:** This scientist explains how inflammation affects the brain and can destroy parts of the brain and the nerve fibers over time, leading to Alzheimer's disease. These scientists also describe research that focuses on destroying the beta-amyloid plaque that builds up in the brain that causes Alzheimer's disease to create an effective vaccine using immunotherapy.

i) "The Benefit of Diet and Exercise in Alzheimer's"

- **Run Time:** 16:46 minutes

- **Key Terms:** lifestyle modifications, oxidative damage, antioxidant rich diet, dog model, exercise, BDNF protein, mouse models
- **Description:** This scientist examines how lifestyle modifications, primarily an antioxidant rich diet and exercise, can affect and even reduce the risk of Alzheimer's disease by studying oxidative damage in the brain.

j) "Cognitive Reserve: What Religious Orders Study is Revealing about Alzheimer's"

- **Run Time:** 22:14 minutes
- **Key Terms:** memory tasks, brain activity, brain imaging, brain regions, brain reserve, Religious Orders Study, brain shrinkage, cognitive reserve
- **Description:** This clips shows the difference in brain MRIs between the brains of an aging adult with no signs of Alzheimer's disease, an older adult with the brain pathology of Alzheimer's disease that is not yet cognitively impaired, and the brain of an older adult with progressive Alzheimer's disease. This clips also details the work of the Religious Orders Study that studies the progression of Alzheimer's disease as it affects the brain with a goal of how to age without memory loss, including the importance of a supportive social network.

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

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

l) "The Pulse of Drug Development"

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

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

- **Run Time:** 25:43 minutes

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

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

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

o) "The Quest for Biomarkers"

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

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

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

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

Programs Available for Purchase

(Listed in order of most recent production date)

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

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

Description:
A blockbuster movie featuring Oscar-winning actress Julianne Moore, based on the book of the same title. Still Alice is the story of Alice Howland, a renowned linguistics professor, happily married with three grown children, who starts to forget words. When she receives a diagnosis of younger-onset Alzheimer's disease, Alice and her family find their bonds thoroughly tested. Her struggle to stay connected to who she once was is frightening, heartbreaking, and inspiring.

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

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

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

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

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

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

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

- **Video Link:** http://www.theconnextion.com/aliveinside/aliveinside_index.cfm
- **Run Time:** 78:00 minutes
- **Key Terms:** music, memory loss, healing
- **Purchase Price:** $14.99

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

- **Video Link:** http://terranova.org/film-catalog/more-than-words/
- **Run Time:** 25:00 minutes

- **Key Terms:** person centered care, communication
- **Purchase Price:**
    - Watch On-Demand 24 hours $19.95
    - Watch On-Demand 2 weeks $45.00
    - Rent DVD $59.00
    - Purchase DVD $179.00

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