Disability Awareness Training

Alzheimer's Disease/ Dementia

Virginia Trainer Manual

2018

Table of Contents

Disability Awareness Training for Law Enforcement

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Opportunities Unlimited of Niagara

Summit Educational Resources

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and Rehabilitation Services
Virginia Department of
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Productions
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Full Circle Studios
Buffalo, New York

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INSTRUCTOR'S NOTE

This working manual was developed with the intent that an individual experienced in training law enforcement and who have some interest and passion in proper response to individuals with alzheimer's disease and other dementias, can accurately and appropriately present on the topic of disability awareness. The content in this manual contains essential and necessary information an officer needs to respond to situations and incidents involving individuals with developmental disabilities. This was developed with direct input from several law enforcement entities and professionals as well as a diverse group of individuals representing the various disabilities. Also providing input were service providers, parent groups, disability advocates, and state offices from Virginia, New York and Missouri.

We made every effort to make this as user-friendly as possible. We understand the challenges of presenting this curriculum with the wide array of information vital to Alzheimer's Disease and demetias.and what it takes for you to communicate this effectively.

PRINCIPLES

The content of this training is based upon the following fundamental premises:

- Police officers encounter individuals with disabilities at least 50% of the time while on active duty.
- Challenging behavior can put Law Enforcement into difficult situations.
- Alzheimer's and dementias will arguably pose the most challenging to Law Enforcement.
- Untrained officers are at a higher risk for a negative encounter.
- Police officers will, oftentimes, be the first to respond to calls and will be called upon to address the situation while respecting quality and dignity of life.
- In interacting with someone with memory loss, law enforcement need to be aware of the appropriate response techniques in order to deescalate certain situations.

ABOUT THIS TRAINING

Niagara University has developed this training to provide law enforcement with a complete and comprehensive understanding of how to respond to individuals with intellectual and devlopmental disabilities in everyday, on-the-job circumstances. That said, there is an extensive amount of material that can be provided to address all the subject matter. This program is designed for you to provide the training as a whole or in modules.

Niagara University's First Responders Disability Awareness Training (NU FRDAT) office provides information, resources and materials that will assist officers in furthering their education on specific disabilities or topics. Part of this outreach includes the disability groups and organizations in your area, allowing training directors and academies an opportunity for Alzheimer's Disease and other dementia connections or training. We encourage first responders to contact us for all their questions and concerns relative to disabilities and how best to respond.

Our website is frdat.niagara.edu or we can be reached at 716-286-7355.

This should be considered the preferred training for any matter relative to response to individuals with Alzheimer's Disease and dementias in Virginia. While your department may have received training from other sources or professionals from the field of developmental disabilities, the training provided in this manual is intended to cover all areas of need most prevalent in your day-to-day line of duty. Our intent is that your time is used wisely, accurately, and appropriately when learning about this very important, and often overlooked, topic.

This program is funded by the **Virginia Department of Criminal Justice Services with support from the Virginia Department of Behavioral Health and Developmental Services and the Virginia Board for People with Disabilities.**

OVERALL OBJECTIVES

- Present relevant, important information about Alzheimer's Disease and various dementias
- Address the challenges officers may face when interacting with individuals with memory loss
- Provide ongoing information and resources to law enforcement relative to Alzheimer's Disease and demetias.
- Provide an understanding of the laws that address proper response to individuals with Alzheimer's Disease and demetias.
- Sensitize and educate officers as to the quality of life issues and overall dignity and respect that can be easily compromised with a lack of proper understanding and response
- Be aware of and utilize the supports that exist for individuals with Alzheimer's Disease and demetias.

CO-PRESENTERS

While you are the lead presenter and have been versed in how to deliver this presentation, you may feel more comfortable with individuals who may have the disability, or who are close to it, such as a parent or service provider professional. These individuals may be best utilized for a specific disability or topic area or as an accompanied presenter throughout your session. They should be considered co-presenters as you will maintain the lead. We encourage individuals that have proven to be accomplished in both disability awareness and the specific disability. NU FR DAT will assist in identifying qualified presenters per your interests. For more information, contact our office or visit our website.

PREPARATION FOR TRAINING

While this manual is designed to guide you through the training program, we understand that there is a lot of new and extensive information that can be overwhelming to both the presenter and the audience. This calls for you to prepare so that the information you provide flows, and our intention is that it is user-friendly. We encourage you to use your creativity when it comes to situations you may have encountered in the line of duty or your peers have communicated to you. Also, it is important to read every handout.

HOW TO USE THIS MANUAL

Each section has a lead page that provides you with the introduction to the topic, its objectives, main points, number of pages, videos, handouts, materials to reference, inserts and the expected duration that it would take to conduct it. Also included are the resources that you can provide to interested attendees. These are discipline-specific and consist mainly of statewide agencies, providers, and associations. Attendees could find the regional programs through the statewide site or contact.

- **Objectives:** this will provide you with the areas that will be covered in this section.

- **Main points:** this gives a brief explanation of the section and what is going to be discussed. You can read this to the audience if you so desire.

- **PowerPoint:** each page of the training is broken down in a note page format. It is designed for you to read to the audience or paraphrase. There will be some direction on certain pages that may indicate questions to be asked or feedback to be received. The intent is to make it easy for you to explain the page and its topic without having to memorize extended content. Customizing pages is encouraged, especially if you have experiences that can provide specifics on a particular disability.

- **Video**: if a video is in this section it will be indicated here. This program is designed to have the videos do the teaching. They expose the audience to the disability, give direction on how to respond, and provide candid comments from individuals. There should be **extended discussion** about each video, and you will see that every point is included on the note page.

- **Handouts:** where appropriate, an additional information sheet(s) is included in the section right after the lead page. PLEASE make a few copies prior to the training to have on hand for those who are interested. Whatever is not taken can be available for the next session.

- **Insert:** some information is provided in the front pocket, this will be indicated when appropriate. They should be shown to the audience and passed around.

- **Resources:** these are discipline-specific and consist mainly of statewide agencies, providers, and associations

BEYOND THIS TRAINING

Niagara University encourages law enforcement personnel to access our website for continued education, review the resource manual and handouts, connect with community resources, and seek out additional training that is specific to each disability or topic area. Any and all questions relative to continuing education are welcome.

Call our office at 716-286-7355 or email us at frdat@niagara.edu.

Introduction/Aging

Objectives:

- Virginia Dementia State Plan explained
- Aging statistics
- Aging process explained
- Causes of functional decline

Main points: According to the Alzheimer's Disease and Related Disorders Commission (VA), an estimated 130,000 Virginians have Alzheimer's Disease and related dementias. Understanding aging, how it progresses, and its inerface with dementia. The commonwealth's state plan includes the development and implmentation oflaw enforcement specific training.

Content:

- PowerPoint: 18 pages

Handout:

- Alzheimer's Association Virginia Statistics

Resources:

- Alzheimer's Association: Phone: 1-800-272-3900: Website: www.alz.org:
- Virginia Department for Aging and Rehabilitative Services: Phone: (804) 662-7000: Website: www.vadars.org
- Virginia Department for Aging and Rehabilitative Services: Phone: (804) 662-7000: Website: www.vadars.org
- Virginia Alzheimer's Disease and Related Disorders Commission Dementia State Plan

ALZHEIMER'S STATISTICS
VIRGINIA

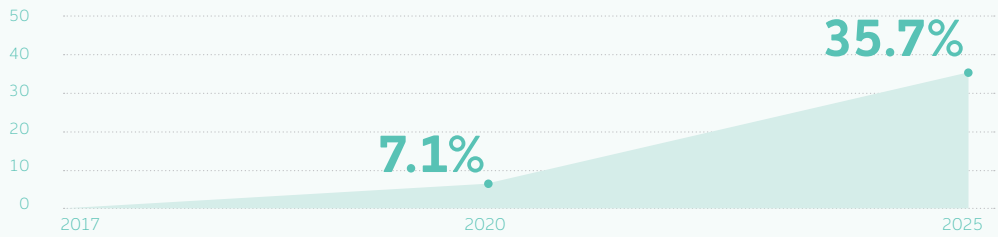
alzheimer's association®
THE BRAINS BEHIND SAVING YOURS.

65+ NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S BY AGE*

Year	65-74	75-84	85+	TOTAL
2017	23,000	61,000	55,000	140,000
2020	26,000	69,000	59,000	150,000
2025	29,000	89,000	68,000	190,000

** Totals may not add due to rounding*

Percentage change from 2017



U.S. STATISTICS

*Over **5 million Americans** are living with Alzheimer's, and as many as **16 million** will have the disease in 2050. The cost of caring for those with Alzheimer's and other dementias is estimated to total **$259 billion** in 2017, increasing to **$1.1 trillion** (in today's dollars) by mid-century. Nearly **one in every three seniors** who dies each year has Alzheimer's or another dementia.*

HOSPICE

of people in hospice with a primary diagnosis of dementia

5,927

% of people in hospice with a primary diagnosis of dementia

21%

MEDICAID COSTS OF CARING FOR PEOPLE WITH ALZHEIMER'S, 2017

$826 MILLION

% change in Medicaid costs from 2017 to 2025

48.7%

NUMBER OF DEATHS FROM ALZHEIMER'S DISEASE IN 2014

1,775

6th *leading cause of death in Virginia*

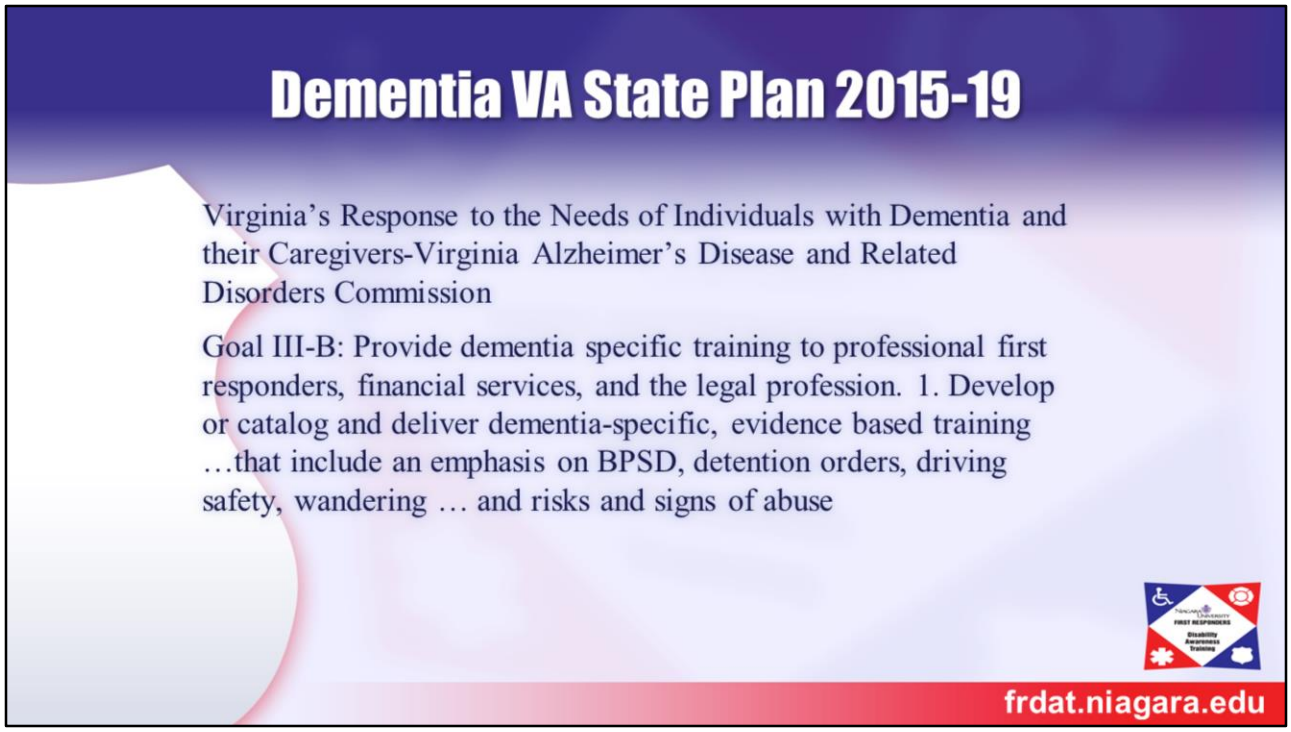
For more information, view the *2017 Alzheimer's Disease Facts and Figures* report at alz.org/facts.

NUMBER OF ALZHEIMER'S AND DEMENTIA CAREGIVERS, HOURS OF UNPAID CARE, AND COSTS OF CAREGIVING

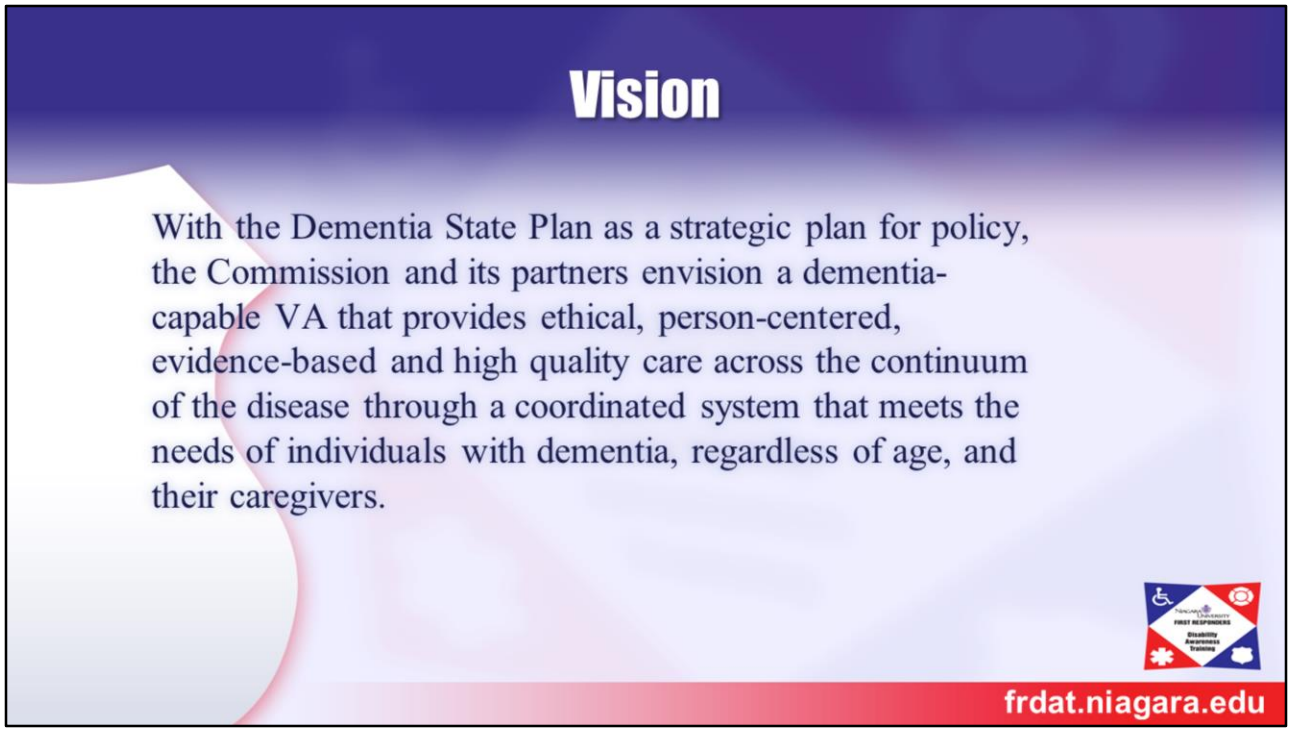
Year	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care	Higher Health Costs of Caregivers
2016	**458,000**	**521,000,000**	**$6,591,000,000**	**$286,000,000**

Handouts:

1.) Alzheimer's Awareness Virginia Statistics



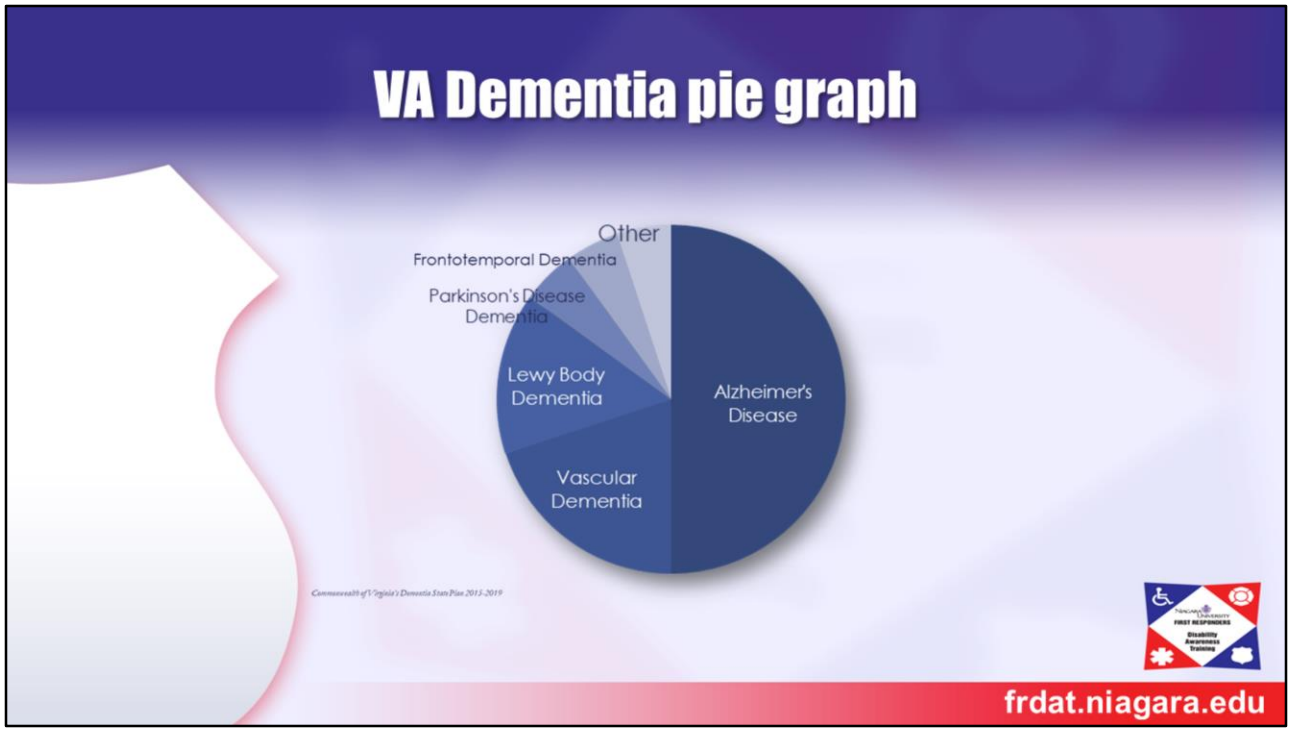
- The State Plan, delivered to the General Assembly October 1, 2015, specifies the need for first responders training.



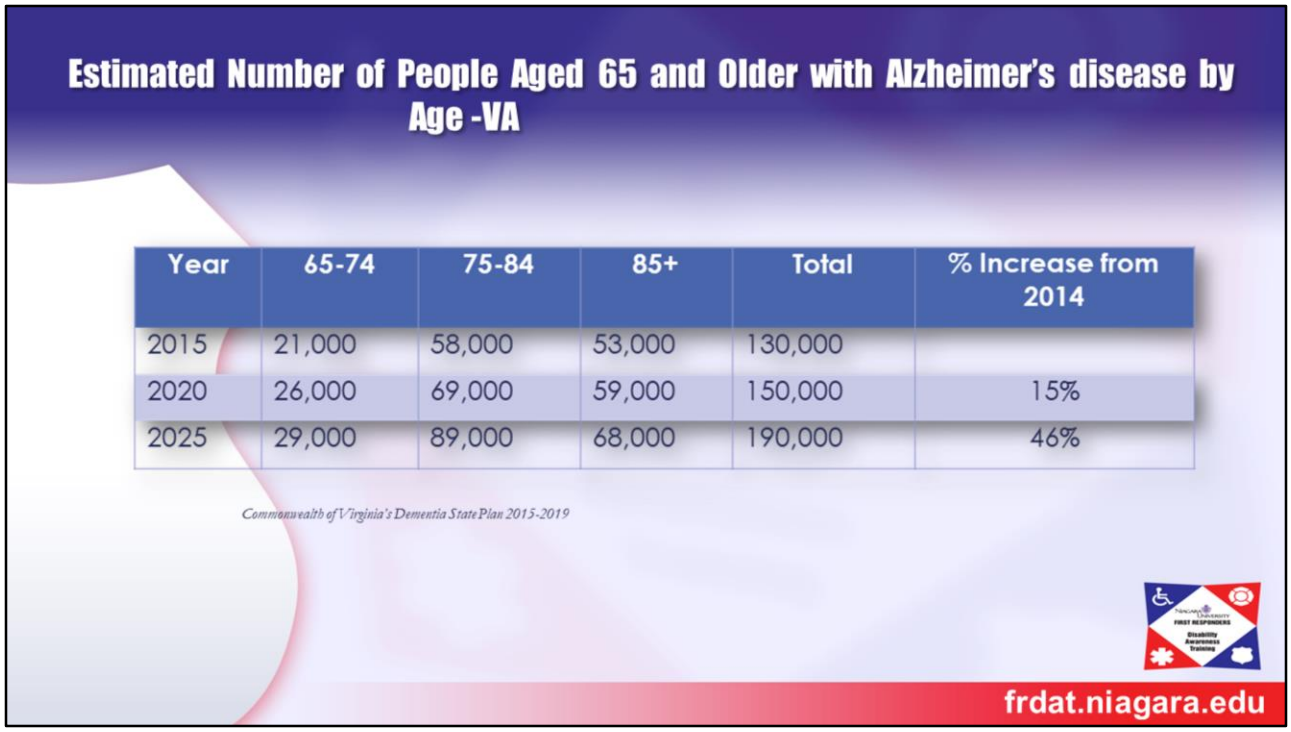
➢ The vision of the State Plan

The five goals of the plan provide a comprehensive vision to:

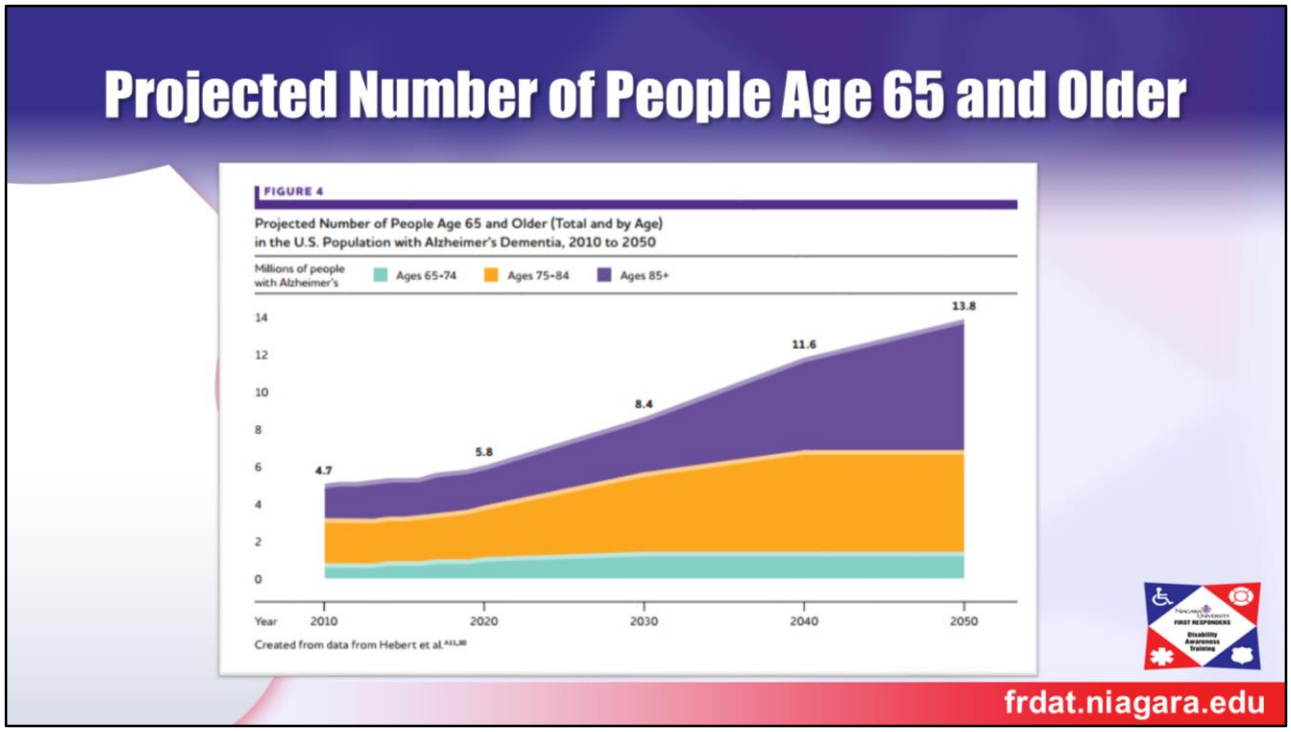
- Coordinate Quality Dementia Services to Ensure Dementia Capability
- Use Dementia Related Data to Improve Public Health
- **Increase Awareness and Create Dementia Specific Training**
- Provide Access to Quality Coordinated Care in the Most Integrated Setting
- Expand Resources for Translational Research and Evidence-Based Practices



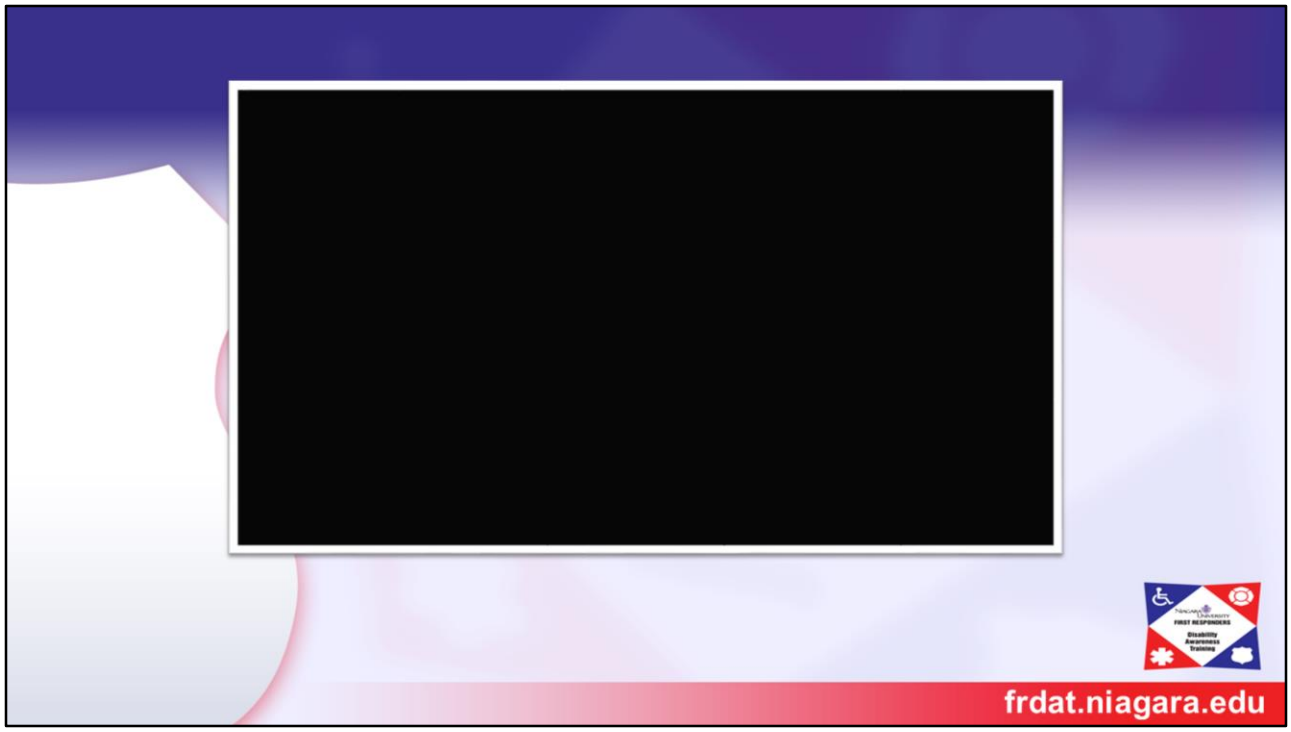
- According to the Alzheimer's Disease and Related Disorders Commission (VA), an estimated 130,000 Virginians have Alzheimer's Disease and related dementias



- Projected numbers in VA

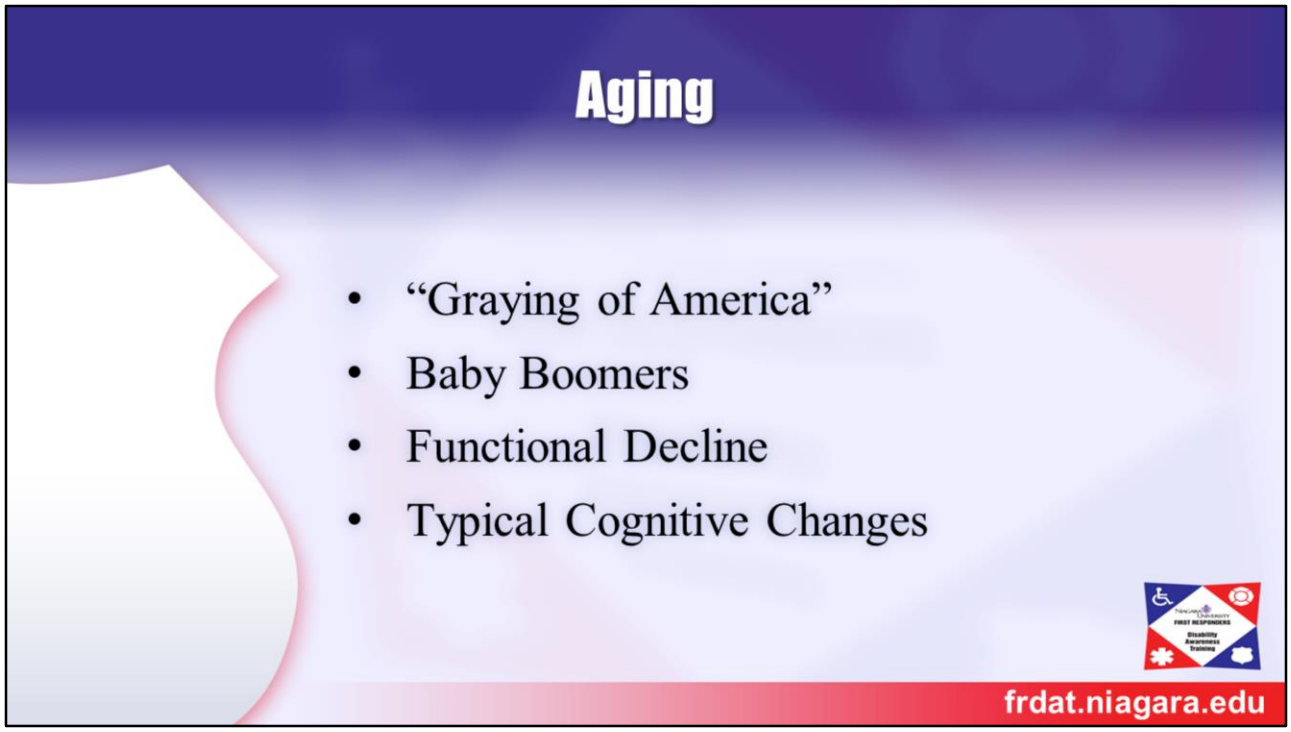


- In 2018, about 2.1 million people who have Alzheimer's dementia are age 85 or older, accounting for 37 percent of all people with Alzheimer's dementia.



2018 Facts and Figures

- Ask the class, “Did you see any numbers that surprised you?”
- Our introduction to the topic
- We will first go over the other dementias



CLICK & READ FIRST TWO BULLETS

- "Baby Boomers:" born between 1946-1964, the first of this population entered their 65th year in 2010. By 2030 there will be 72 million people over the age of 65.
- Along with this upswing in the "young-elderly" there will be a corresponding upswing in what is now called the "old-elderly." Increasingly, there will be many who face not only functional decline, but also dementia.
- More elders are able to stay at home these days, however this positive opportunity has its challenges as well. Caregivers, whether family members or others, experience stress, depression and burnout.

CLICK AND READ THIRD BULLET

- Functional decline is described as the inability to perform usual activities of daily living due to weakness, reduced muscle strength, and reduced exercise capacity. It includes

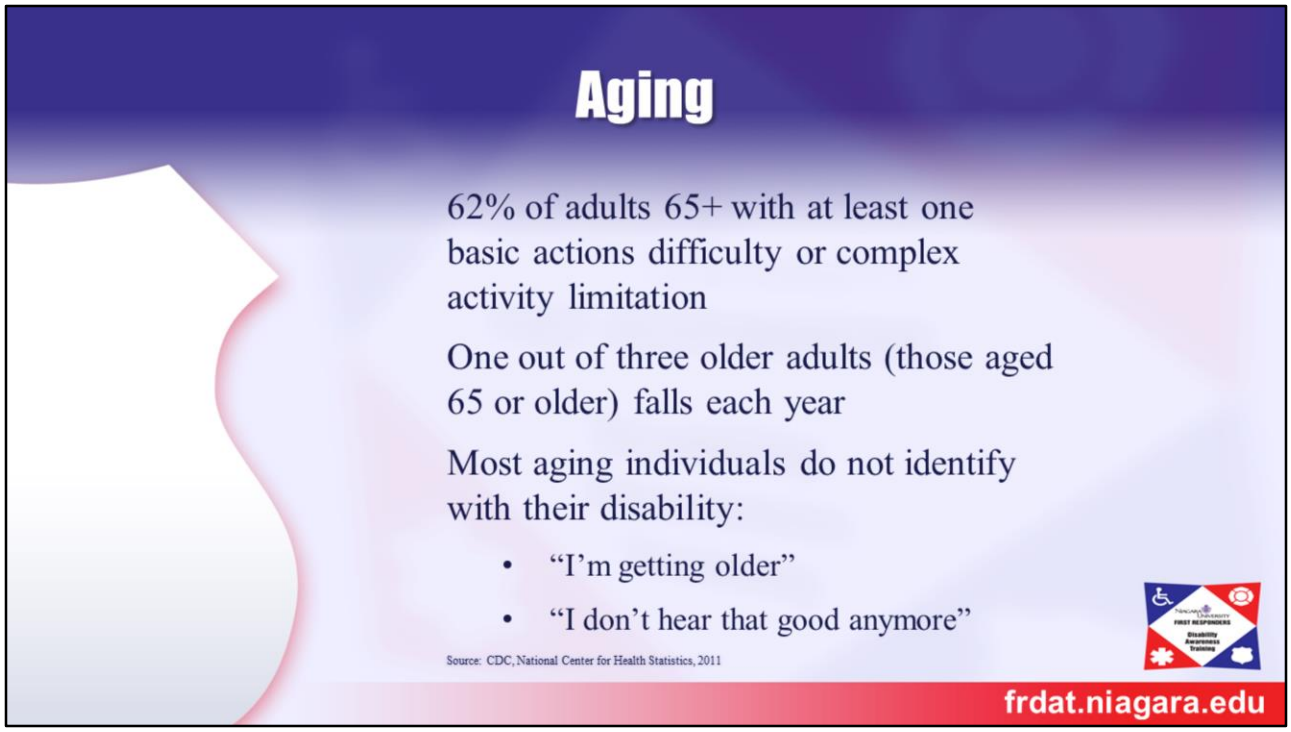
physical changes such as reductions in strength, bone density, breathing ability, vision, hearing (all senses), and blood pressure fluctuation.

(https://www.ncbi.nlm.nih.gov/books/NBK2629/ Ruth M. Kleinpell; Kathy Fletcher; Bonnie M. Jennings. Chapter 11Reducing Functional Decline in Hospitalized Elderly. Hughes RG, editor.
Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Apr.)

- When combined with chronic health care conditions that are most prevalent in the elderly, including heart disease, hypertension, arthritis, diabetes, cancer, and various forms of dementia, many individuals will need more assistance from first responders.

CLICK AND READ FOURTH BULLET

- As people age, it is typical for some slowing of cognitive speed and memory



CLICK AND READ 5 POINTS

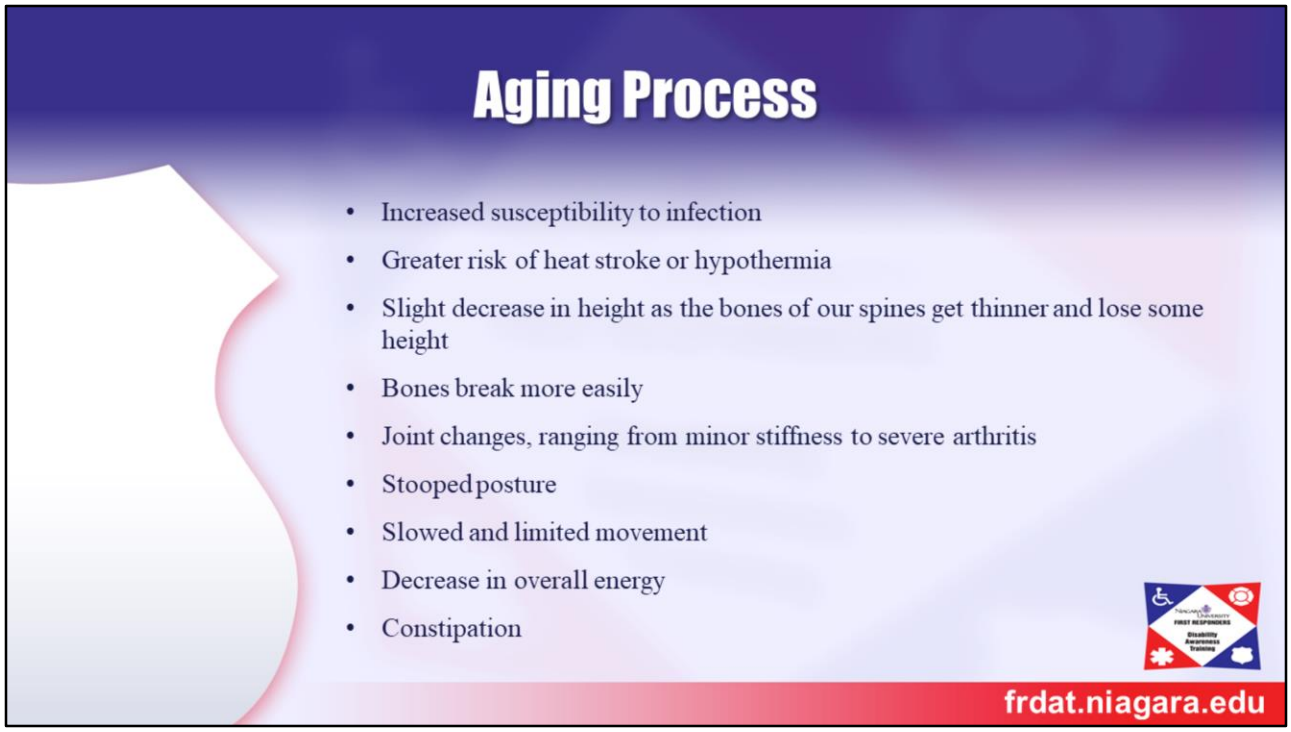
- The incidence of disability greatly increases as we age.
- We need to understand Aging to understand dementias.
- Aging is "the great equalizer." If we live long enough, we will join the disability community.
- In 2013, 2.5 million nonfatal falls among older adults were treated in emergency departments and more than 734,000 of these patients were hospitalized (CDC).
- However, most seniors do not identify with their new disabilities but see it more as part of the aging process.

CLICK AND READ SLIDE

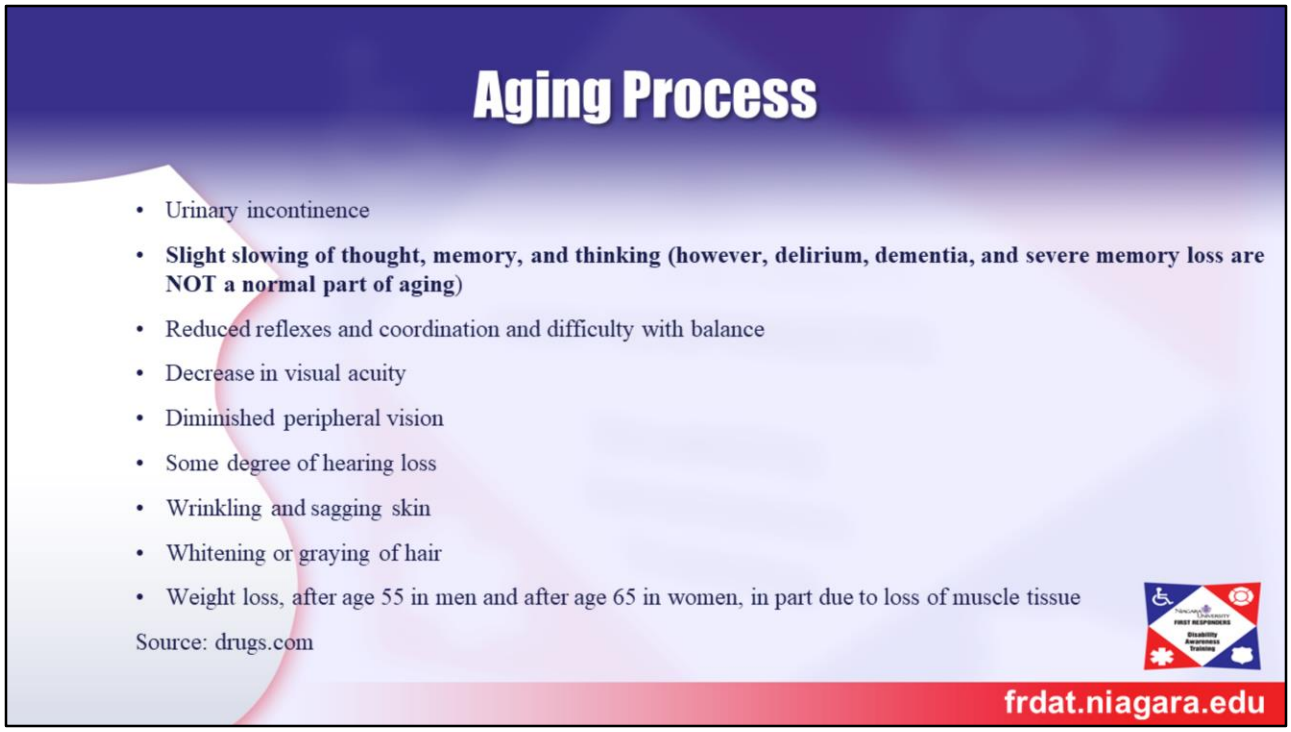
- Basic definition of disability, next page identifies those major life activities.
- Key to this definition is “substantially limits.” While people might have limitations, to what degree does it affect their ability to function?

CLICK AND READ 13 BULLETS, ENDING WITH REACHING

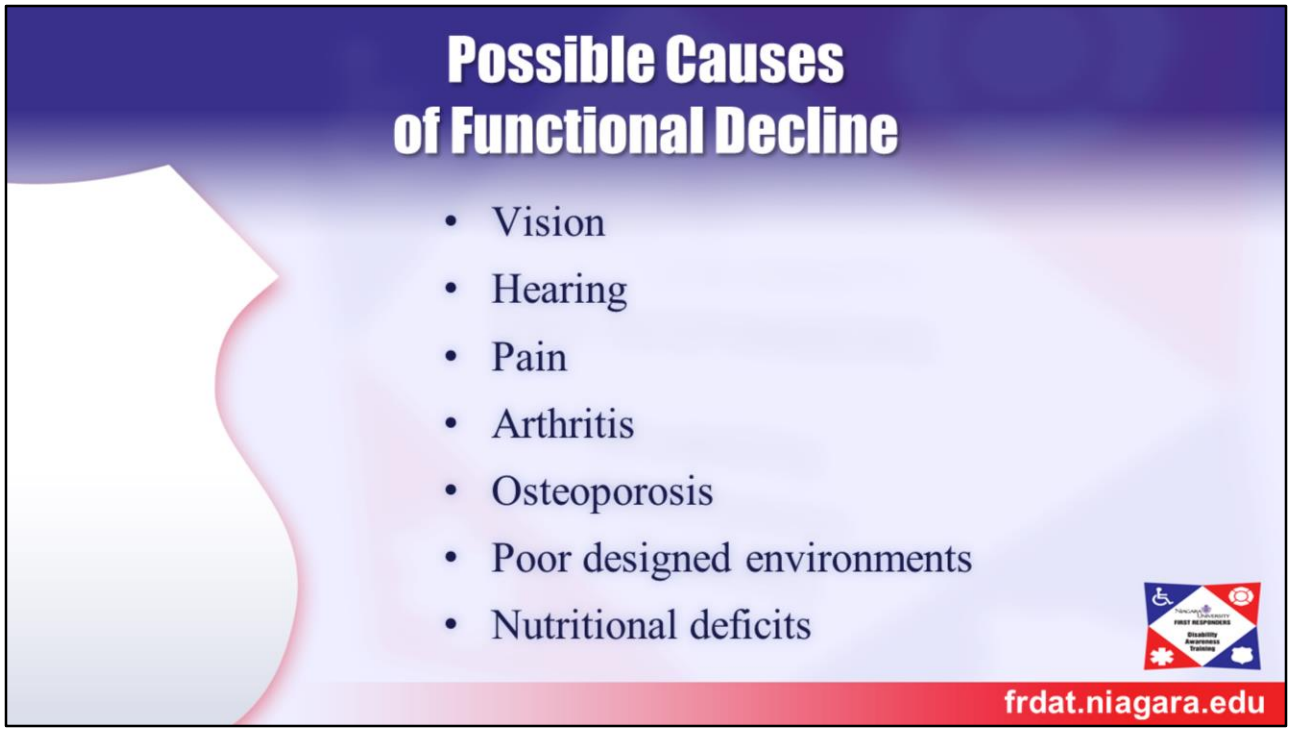
If one of these is affected in a manner where it substantially limits you from functioning, you meet the definition of disability.



- Aging is a natural part of human existence
- Within the process is susceptibility to medical or physical conditions

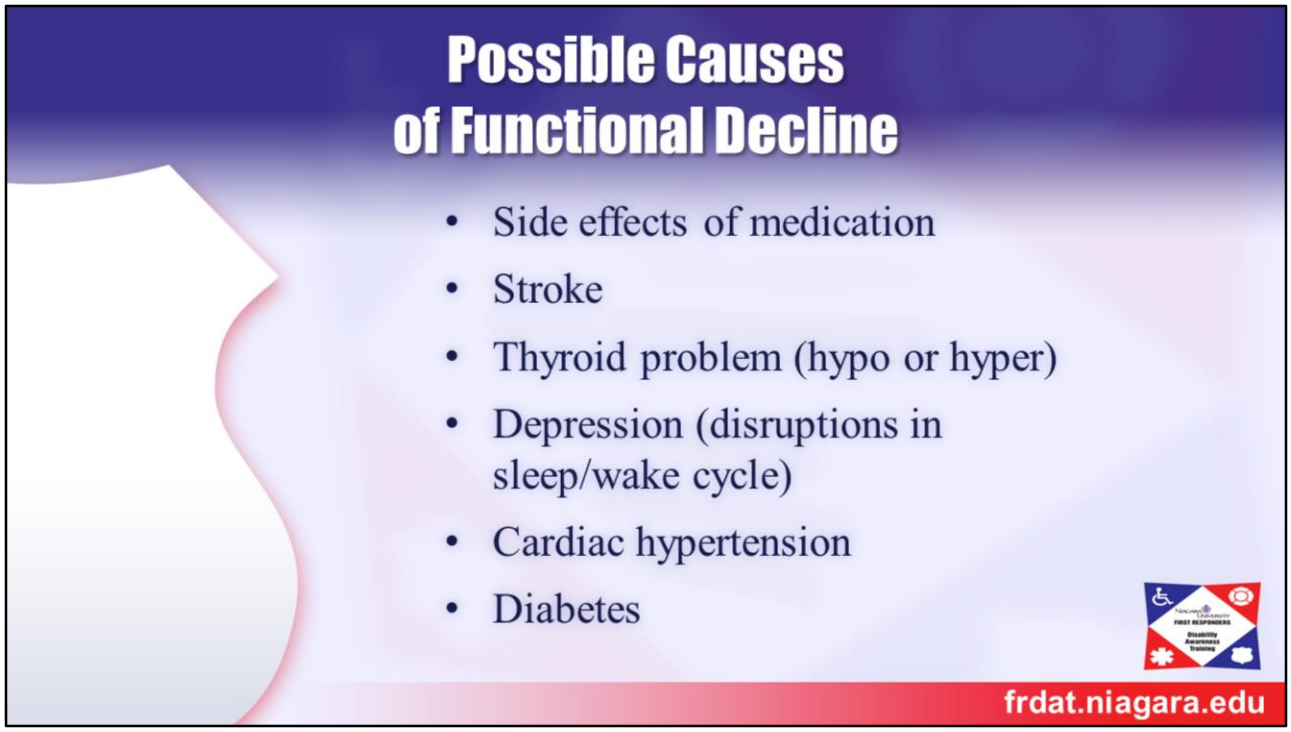


- Note that delirium, dementia, and severe memory loss is NOT part of the normal aging process
- While slight memory loss is related to aging, **severe** memory loss is not.
- Note the sensory losses in vision and hearing



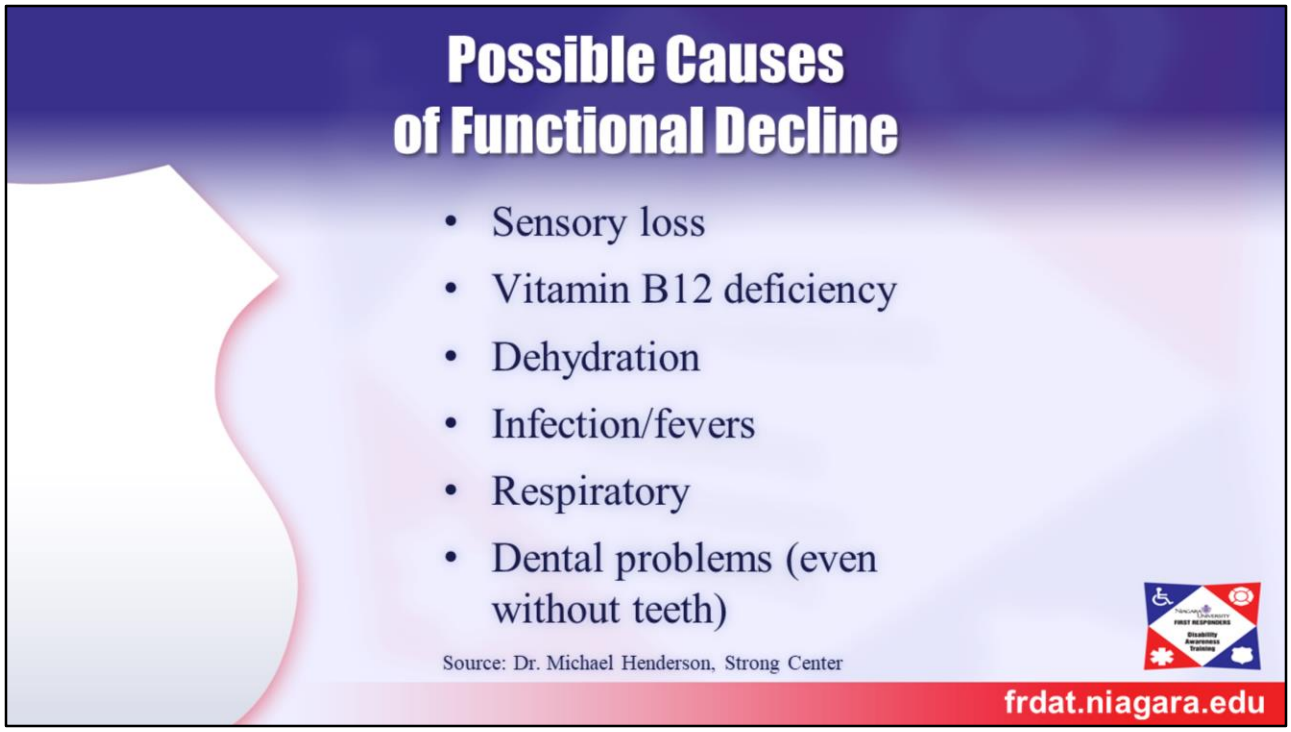
CLICK AND READ 7 BULLETS

- This defines how we functionally decline with age through the various conditions that may come upon us.
- As you interact with seniors, any one of these may be compromised or serve as a reason for new challenges.
- Oversight by adult children and caregivers of the aging senior lead to a lack of recognition of the need to rearrange furniture for clearer paths, remove rugs, and ensuring accessibility.



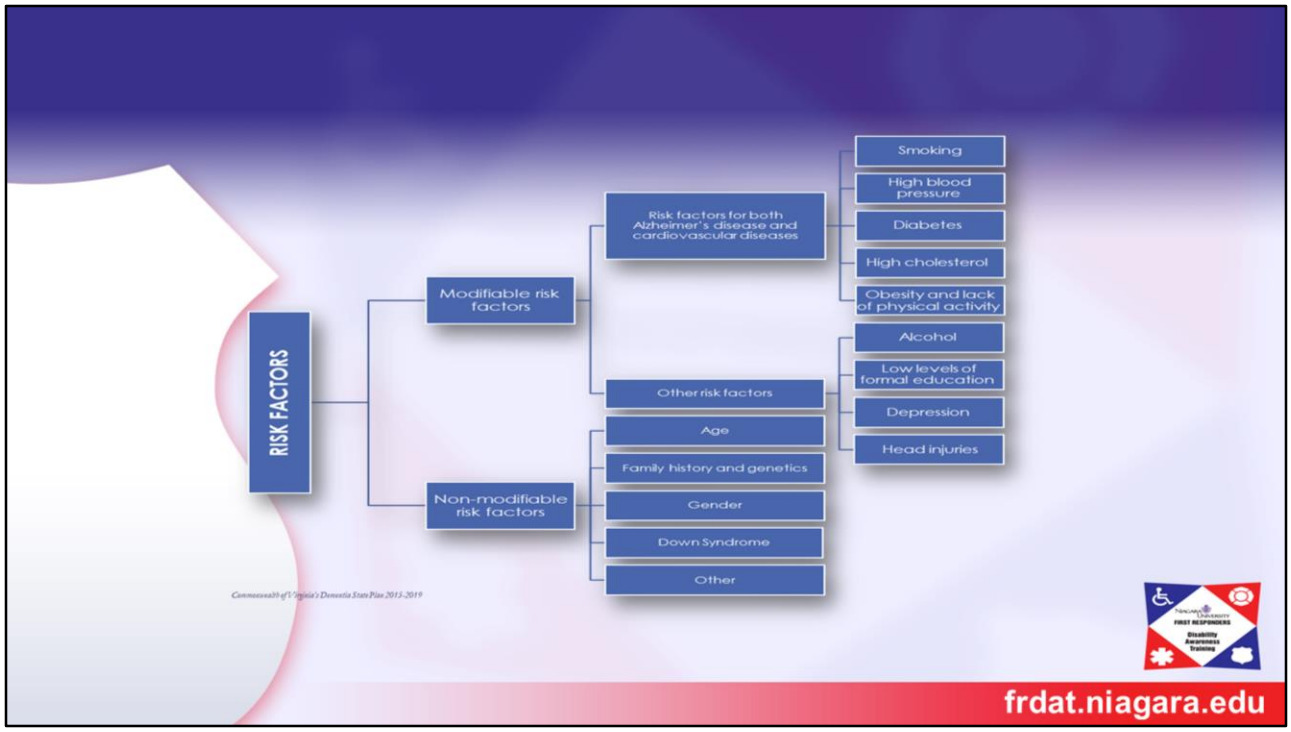
CLICK AND READ 6 BULLETS

This is a continuation from the previous slide.



CLICK AND READ 6 BULLETS

This is a continuation from the previous slide.



- Risk factors include: family history, APOE 34 gene, mild cognitive impairment, cardiovascular risk factors, social and cognitive engagement, education (degree of), and traumatic brain injury specific to the Commonwealth as it relates to Dementia
- Note some are within a person's control, such as use of tobacco and alcohol or healthy eating habits
- The percentage of people with Alzheimer's dementia as it relates to age are as follows:
  - 3% of people age 65-74
  - 17% age 75-84
  - 32% age 85+
- Of people with Alzheimer's Disease, 81% are age 75+
- Of people age 65+, 3.4M are women, 2M are men

Dementias

Objectives:

- Dementia vs Alzheimer's explained
- Behavior changes
- Speech disorders and dementia
- Frontal Temporal Dementia Defined
- Lewy Body Dementia Defined
- Parkinson's disease defined

Main points: Dementia is a public health crisis and law enforcement will encounter someone with the disease. Dementia is a symptom that is associated with 13 different brain disorders, the most common being Alzheimer's disease. Characteristics are similar in that memory, language and functioning will be affected. Alzheimer's disease accounts for 70% of dementia and is a leading cause of death amongst seniors. People with dementia may be confused and not be aware of time, place, or surroundings, even though it was once routine.

Content:

- PowerPoint: 30 pages
- Videos:
    - Michael J. Fox Foundation Parkinson's Video

Handouts:

- Alzheimer's Disease and Other Dementias
- Vascular Dementia
- Frontotemporal Dementia
- Parkinson's Disease
- Lewy Body Fact Sheet

Resources:

- University of Virginia Health Systems/University Parkinson's Disease & Movement Disorder Clinic: Phone: 434-924-2706 :Website: uvahealth.com
- VCU Medical Center/Parkinson's & Movement Disorders Center: Website:parkinsons.vcu.edu
- Parkinson's Foundation: Phone: 1-800-473-4636: Website: www.parkinson.org
- Lewy Body Dementia Association: Website: www.lbda.org

Alzheimer's Disease and Other Dementias

About dementia
Dementia is a general term for a group of brain disorders. Alzheimer's disease is the most common type of dementia, accounting for 60 to 80 percent of cases. This fact sheet briefly discusses Alzheimer's and some other dementias.

All types of dementia involve mental decline that:

- occurred from a higher level (for example, the person didn't always have a poor memory)
- is severe enough to interfere with usual activities and daily life
- affects more than one of the following four core mental abilities
- recent memory (the ability to learn and recall new information)
- language (the ability to write or speak, or to understand written or spoken words)
- visuospatial function (the ability to understand and use symbols, maps, etc., and the brain's ability to translate visual signals into a correct impression of where objects are in space)
- executive function (the ability to plan, reason, solve problems and focus on a task)

Alzheimer's disease
Although symptoms can vary widely, the first problem many people with Alzheimer's notice is forgetfulness severe enough to affect their work, lifelong hobbies or social life. Other symptoms include confusion, trouble with organizing and expressing thoughts, misplacing things, getting lost in familiar places, and changes in personality and behavior.

These symptoms result from damage to the brain's nerve cells. The disease gradually gets worse as more cells are damaged and destroyed. Scientists do not yet know why brain cells malfunction and die, but two prime suspects are abnormal microscopic structures called plaques and tangles. For more detailed information about Alzheimer's disease, please visit our Web site www.alz.org or contact us at 1.800.272.3900.

Mild cognitive impairment (MCI)
In MCI, a person has problems with memory or one of the other core functions affected by dementia. These problems are severe enough to be noticeable to other people and to show up on tests of mental function, but not serious enough to interfere with daily life. When symptoms do not disrupt daily activities, a person does not meet criteria for being diagnosed with dementia. The best-studied type of MCI involves a memory problem.

Individuals with MCI have an increased risk of developing Alzheimer's disease over the next few years, especially when their main problem involves memory. However, not everyone diagnosed with MCI progresses to Alzheimer's or another kind of dementia.

Vascular dementia (VaD)
Many experts consider vascular dementia the second most common type, after Alzheimer's disease. It occurs when clots block blood flow to parts of the brain, depriving nerve cells of

food and oxygen. If it develops soon after a single major stroke blocks a large blood vessel, it is sometimes called "post-stroke dementia."

It can also occur when a series of very small strokes, or infarcts, clog tiny blood vessels. Individually, these strokes do not cause major symptoms, but over time their combined effect is damaging. This type used to be called "multi-infarct dementia."

Symptoms of vascular dementia can vary, depending on the brain regions involved. Forgetfulness may or may not be a prominent symptom, depending on whether memory areas are affected. Other common symptoms include difficulty focusing attention and confusion. Decline may occur in "steps," where there is a fairly sudden change in function.

People who develop vascular dementia may have a history of heart attacks. High blood pressure or cholesterol, diabetes or other risk factors for heart disease are often present.

Mixed dementia
In mixed dementia, Alzheimer's disease and vascular dementia occur at the same time. Many experts believe mixed dementia develops more often than was previously realized and that it may become increasingly common as people age. This belief is based on autopsies showing that the brains of up to 45 percent of people with dementia have signs of both Alzheimer's and vascular disease.

Decline may follow a pattern similar to either Alzheimer's or vascular dementia or a combination of the two. Some experts recommend suspecting mixed dementia whenever a person has both (1) evidence of cardiovascular disease and (2) dementia symptoms that get worse slowly.

Dementia with Lewy bodies (DLB)
In DLB, abnormal deposits of a protein called alpha-synuclein form inside the brain's nerve cells. These deposits are called "Lewy bodies" after the scientist who first described them. Lewy bodies have been found in several brain disorders, including dementia with Lewy bodies, Parkinson's disease and some cases of Alzheimer's.

Symptoms of DLB include:

- Memory problems, poor judgment, confusion and other symptoms that can overlap with Alzheimer's disease
- Movement symptoms are also common, including stiffness, shuffling walk, shakiness, lack of facial expression, problems with balance and falls
- Excessive daytime drowsiness
- Visual hallucinations
- Mental symptoms and level of alertness may get better or worse (fluctuate) during the day or from one day to another
- In about 50 percent of cases, DLB is associated with a condition called rapid eye movement (REM) sleep disorder. REM sleep is the stage where people usually dream. During normal REM sleep, body movement is blocked and people do not "act out" their dreams. In REM sleep disorder, movements are not blocked and people act out their dreams, sometimes vividly and violently.

Parkinson's disease (PD)
Parkinson's is another disease involving Lewy bodies. The cells that are damaged and destroyed are chiefly in a brain area important in controlling movement. Symptoms include tremors and shakiness; stiffness; difficulty with walking, muscle control, and balance; lack of facial expression; and impaired speech. Many individuals with Parkinson's develop dementia in later stages of the disease.

Frontotemporal dementia (FTD)
FTD is a rare disorder chiefly affecting the front and sides of the brain. Because these regions often, but not always, shrink, brain imaging can help in diagnosis. There is no specific abnormality found in the brain in FTD. In one type called Pick's disease, there are sometimes (but not always) abnormal microscopic deposits called Pick bodies.

FTD progresses more quickly than Alzheimer's disease and tends to occur at a younger age. The first symptoms often involve changes in personality, judgment, planning and social skills. Individuals may make rude or off-color remarks to family or strangers, or make unwise decisions about finances or personal matters. They may show feelings disconnected from the situation, such as indifference or excessive excitement. They may have an unusually strong urge to eat and gain weight as a result.

Creutzfeldt-Jakob disease (CJD)
Creutzfeldt-Jakob disease (pronounced CROYZ-felt YAH-cob) is a rare, rapidly fatal disorder affecting about 1 in a million people per year worldwide. It usually affects individuals older than 60. CJD is one of the prion (PREE-awn) diseases. These disorders occur when prion protein, a protein normally present in the brain, begins to fold into an abnormal three-dimensional shape. This shape gradually triggers the protein throughout the brain to fold into the same abnormal shape, leading to increasing damage and destruction of brain cells.

Recently, "variant Creutzfeldt-Jakob disease" (vCJD) was identified as the human disorder believed to be caused by eating meat from cattle affected by "mad cow disease." It tends to occur in much younger individuals, in some cases as early as their teens.

The first symptoms of CJD may involve impairment in memory, thinking and reasoning or changes in personality and behavior. Depression or agitation also tend to occur early. Problems with movement may be present from the beginning or appear shortly after the other symptoms. CJD progresses rapidly and is usually fatal within a year.

Normal pressure hydrocephalus (NPH)
Normal pressure hydrocephalus (high-droh-CEFF-a-luss) is another rare disorder in which fluid surrounding the brain and spinal cord is unable to drain normally. The fluid builds up, enlarging the ventricles (fluid-filled chambers) inside the brain. As the chambers expand, they can compress and damage nearby tissue. "Normal pressure" refers to the fact that the spinal fluid pressure often, although not always, falls within the normal range on a spinal tap.

The three chief symptoms of NPH are (1) difficulty walking, (2) loss of bladder control and (3) mental decline, usually involving an overall slowing in understanding and reacting to

information. A person's responses are delayed, but they tend to be accurate and appropriate to the situation when they finally come.

NPH can occasionally be treated by surgically inserting a long thin tube called a shunt to drain fluid from the brain to the abdomen. Certain television broadcasts and commercials have portrayed NPH as a highly treatable condition that is often misdiagnosed as Alzheimer's or Parkinson's disease. However, most experts believe it is unlikely that significant numbers of people diagnosed with Alzheimer's or Parkinson's actually have NPH that could be corrected with surgery. NPH is rare, and it looks different from Alzheimer's or Parkinson's to a physician with experience in assessing brain disorders. When shunting surgery is successful, it tends to help more with walking and bladder control than with mental decline.

Huntington's disease (HD)
HD is a fatal brain disorder caused by inherited changes in a single gene. These changes lead to destruction of nerve cells in certain brain regions. Anyone with a parent with Huntington's has a 50 percent chance of inheriting the gene, and everyone who inherits it will eventually develop the disorder. In about 1 to 3 percent of cases, no history of the disease can be found in other family members. The age when symptoms develop and the rate of progression vary.

Symptoms of Huntington's disease include twitches, spasms, and other involuntary movements; problems with balance and coordination; personality changes; and trouble with memory, concentration or making decisions.

Wernicke-Korsakoff syndrome
Wernicke-Korsakoff syndrome is a two-stage disorder caused by a deficiency of thiamine (vitamin B-1). Thiamine helps brain cells produce energy from sugar. When levels of the vitamin fall too low, cells are unable to generate enough energy to function properly. Wernicke encephalopathy is the first, acute phase, and Korsakoff psychosis is the long-lasting, chronic stage.

The most common cause is alcoholism. Symptoms of Wernicke-Korsakoff syndrome include:

- confusion, permanent gaps in memory and problems with learning new information
- individuals may have a tendency to "confabulate," or make up information they can't remember
- unsteadiness, weakness and lack of coordination

If the condition is caught early and drinking stops, treatment with high-dose thiamine may reverse some, but usually not all, of the damage. In later stages, damage is more severe and does not respond to treatment.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Updated February 2009

Vascular dementia

A topic in the Alzheimer's Association® series on understanding dementia.

About dementia
Dementia is a condition in which a person has significant difficulty with daily functioning because of problems with thinking and memory. Dementia is not a single disease; it's an overall term — like heart disease — that covers a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behavior, feelings and relationships.

Brain changes that cause dementia may be temporary, but they are most often permanent and worsen, leading to increasing disability and a shortened life span. Survival can vary widely, depending on such factors as the cause of the dementia, age at diagnosis and coexisting health conditions.

Vascular dementia
Vascular dementia is a decline in thinking skills caused by conditions that block or reduce blood flow to various regions of the brain, depriving them of oxygen and nutrients. Inadequate blood flow can damage and eventually kill cells anywhere in the body, but the brain is especially vulnerable.

In vascular dementia, changes in thinking skills sometimes occur suddenly after a stroke, which blocks major blood vessels in the brain. Thinking difficulties may also begin as mild changes that gradually worsen as a result of multiple minor strokes or another condition that affects smaller blood vessels, leading to widespread damage. A growing number of experts prefer the term "vascular cognitive impairment" (VCI) to "vascular dementia" because they feel it better expresses the concept that vascular thinking changes can range from mild to severe.

Vascular brain changes often coexist with changes linked to other types of dementia, including Alzheimer's disease and dementia with Lewy bodies. Several studies have found that vascular changes and other brain abnormalities may interact in ways that increase the likelihood of dementia diagnosis.

Prevalence
Vascular dementia is widely considered the second most common cause of dementia after Alzheimer's disease. It is very common in older individuals with dementia, with

about 50 percent having pathologic evidence of vascular dementia, known as infarcts. In most cases, the infarcts coexist with Alzheimer's pathology. Many experts are concerned that vascular dementia remains underdiagnosed — like Alzheimer's disease — even though it's recognized as a common disease. It's important to better understand the full extent of vascular dementia and dementia overall because there are well-supported strategies, including diet, exercise and medication, to reduce overall risk of diseases of the heart and blood vessels, including those in the brain.

Symptoms

The impact of vascular conditions on thinking skills varies widely, depending on the severity of the blood vessel damage and the part of the brain it affects. Memory loss may or may not be a significant symptom depending on the specific brain areas where blood flow is reduced. Vascular damage that starts in the brain areas that play a key role in storing and retrieving information may cause memory loss that is very similar to Alzheimer's disease.

Symptoms due to vascular dementia may be most obvious when they happen soon after a major stroke. Sudden post-stroke changes in brain function may include confusion; disorientation; trouble speaking or physical stroke symptoms, such as a sudden headache; difficulty walking, poor balance, or numbness or paralysis on one side of the face or the body. Severe depression is common in individuals with vascular dementia, more so than in people with Alzheimer's disease.

Multiple small strokes or other conditions that affect blood vessels and nerve fibers deep inside the brain may cause more gradual thinking changes as damage accumulates. Common early signs of widespread small vessel disease are impaired planning and judgment, uncontrolled laughing and crying, declining ability to pay attention, impaired function in social situations and difficulty finding the right words.

Diagnosis

Diagnostic guidelines for vascular dementia have used a range of definitions for dementia and various approaches to diagnosis. In 2011, the American Heart Association and American Stroke Association issued a joint scientific statement on vascular contributions to mild cognitive impairment (MCI) and dementia. The Alzheimer's Association participated in developing the statement, which is also endorsed by the American Academy of Neurology. The goals of the statement, which include practice recommendations, are to raise awareness of the importance of vascular factors in cognitive change, increase diagnostic consistency and accelerate research.

Under the diagnostic approach recommended in the statement, the following criteria suggest the greatest likelihood of MCI or dementia is caused by vascular changes:

1. The diagnosis of dementia or MCI is confirmed by neurocognitive testing.
2. There is brain imaging evidence, usually with magnetic resonance imaging (MRI), confirming:
    a. A recent stroke.
    b. Other vascular brain changes whose severity and pattern of affected tissue are consistent with the types of impairment documented in cognitive testing.
    c. There is no evidence that nonvascular factors may be contributing to cognitive decline.

The statement also details variations in these criteria that may suggest a possibility rather than a strong likelihood that cognitive change is due to vascular factors.

Because vascular dementia often goes unrecognized, many experts recommend professional cognitive screening for everyone considered to be at high risk, including those who have had a stroke or a transient ischemic attack (TIA), also known as a ministroke, or who have risk factors for heart or blood vessel disease. Professional screening for depression is also recommended for high-risk groups. Depression commonly coexists with brain vascular disease and can contribute to cognitive impairment.

Causes and risk factors

Any condition that damages blood vessels anywhere in the body can cause brain changes linked to vascular dementia. As with Alzheimer's disease, advancing age is a major risk factor.

Additional risk factors for vascular dementia coincide with those that increase risk for heart disease, stroke and other conditions affecting blood vessels. Many of these factors are also linked to increased risk of Alzheimer's. The following strategies may reduce the risk of developing diseases that affect the heart and blood vessels — and may help protect the brain:

- Don't smoke.
- Keep blood pressure, cholesterol and blood sugar within recommended limits.
- Eat a healthy, balanced diet.
- Exercise.
- Maintain a healthy weight.

- Limit alcohol consumption.

Outcomes

Like other types of dementia, vascular dementia shortens life span. Some data suggest that those who develop dementia following a stroke survive an average of three years. As with other stroke symptoms, cognitive changes may sometimes improve during recovery and rehabilitation from the acute phase of a stroke as the brain generates new blood vessels and brain cells outside the damaged region take on new roles.

Treatment

The U.S. Food and Drug Administration (FDA) has not approved any drugs specifically to treat symptoms of vascular dementia, but there is evidence from clinical trials that drugs approved to treat Alzheimer's symptoms may also offer a modest benefit in people with vascular dementia. Pharmacological treatment primarily works to prevent the worsening of vascular dementia by treating the underlying disease, such as hypertension, hyperlipidemia or diabetes mellitus.

Controlling risk factors that may increase the likelihood of further damage to the brain's blood vessels is an important treatment strategy. There's substantial evidence that treatment of risk factors may improve outcomes and help postpone or prevent further decline.

Individuals should work with their physicians to develop the best treatment plan for their symptoms and circumstances.

TS-0098 | Updated June 2018

Frontotemporal dementia (FTD)

A topic in the Alzheimer's Association® series on understanding dementia.

About dementia

Dementia is a condition in which a person has significant difficulty with daily functioning because of problems with thinking and memory. Dementia is not a single disease; it's an overall term — like heart disease — that covers a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behavior, feelings and relationships.

Brain changes that cause dementia may be temporary, but they are most often permanent and worsen, leading to increasing disability and a shortened life span. Survival can vary widely, depending on such factors as the cause of the dementia, age at diagnosis and coexisting health conditions.

Frontotemporal dementia or frontotemporal degenerations

Frontotemporal dementia refers to a group of disorders that cause progressive nerve cell loss in the frontal and temporal lobes of the brain. The nerve cell damage leads to loss of function in these brain regions, which can variably cause deterioration in behavior and personality, language disturbances or alterations in muscle and motor functions.

There are a number of different diseases that cause frontotemporal degenerations. The two most prominent are a group of brain disorders involving tau protein and others involving TDP43 protein. For reasons that are not yet known, these two groups tend to accumulate in the frontal and temporal lobes.

Behavior variant frontotemporal dementia

Behavior variant frontotemporal dementia (bvFTD) is a condition characterized by prominent changes in personality, interpersonal relationships and conduct that often occurs in people in their 50s and 60s but can develop as early as their 20s or as late as their 80s. The most common behaviors are caused by the degeneration of neuronal cells in the frontotemporal area of the brain. In bvFTD, the nerve cell loss is most prominent in areas that control conduct, judgment, understanding of how other people feel (empathy) and foresight, among other abilities.

BvFTD is suspected as a diagnosis when a person who previously exhibited normal behavior and judgment shows changes in personality, interpersonal skills and other daily behaviors. The changes in personality might include disinterest in prior pastimes or family affairs. BvFTD could lead to loss of interpersonal skills that may result in more socially inappropriate activities, such as making inappropriate comments or acting in demeaning, rude or immodest fashion. In addition, a loss of empathy is common and catastrophically poor judgment could lead to major financial or personal crises.

Primary progressive aphasia

Primary progressive aphasia (PPA) is the other major form of frontotemporal degeneration. Aphasia refers to a disorder of language that can involve problems with speaking, writing or comprehension. The "primary progressive" refers to the usual way in which PPA occurs, namely first and foremost as a disorder of language. PPA normally develops before the age of 65 but can also occur in late life. In contrast to bvFTD, the brain degeneration that occurs in PPA tends to be much more limited to the left hemisphere of the brain, where, for most people, language functions in the brain are located. Different speech and language difficulties arise depending on where the brunt of the degeneration occurs, which could include the left frontal, temporal or parietal lobes.

The two most distinctive PPA subtypes are one called nonfluent/agrammatic variant of PPA, in which speaking is very hesitant, labored, stuttered and telegraphic. The other distinctive PPA subtype is called the semantic variant of PPA, where the affected individual loses the ability to understand or formulate words in a spoken sentence.

Disturbances of motor (movement or muscle) function in frontotemporal degenerations

Three disorders on the frontotemporal degeneration spectrum produce changes in muscle or motor functions with or without behavior changes (such as in bvFTD) or problems with language (like those in PPA). The first, amyotrophic lateral sclerosis (ALS, also known as motor neuron disease or Lou Gehrig's disease), is a disorder of muscle weakness and wasting. The second, corticobasal syndrome, is a disorder in which the arms and legs become uncoordinated and stiff. The third, progressive supranuclear palsy (PSP), is a disorder in which there are problems with eye movement, as well as muscle stiffness, difficulty walking and changes in posture.

These disorders share the same abnormal changes in the brain that occur in bvFTD and PPA except that the nerve cell degenerative changes are primarily in parts of the

brain that affect the motor nerve cells responsible for coordinating muscle movement rather than behavior or language.

Prevalence of frontotemporal degenerations

Both bvFTD and PPA are far less common than Alzheimer's disease in individuals over age 65. However, in the 45 to 65 age range, bvFTD and PPA are nearly as common as younger-onset Alzheimer's disease. Only rough estimates are available, but there may be 50,000 to 60,000 people with bvFTD or PPA in the United States — the vast majority between ages 45 and 65. It is rare that these disorders occur outside of this age range.

In the United States, more than 14,000 people have ALS, and approximately five people in every 100,000 have PSP.

Diagnosis

Diagnoses of bvFTD and PPA are based on expert evaluation by a physician who is familiar with these disorders. The patient's symptoms and results from neurological examinations are the core of the diagnosis. Brain scans such as magnetic resonance imaging (MRI) and glucose positron emission scans are helpful diagnostic tests but must be evaluated together with the patient's medical history and neurological examination. Occasionally a psychiatric evaluation will also be ordered as part of the diagnostic process, such as when it is unclear if changes in behavior are due to depression or another psychiatric disturbance.

Since a decline in language abilities is the primary symptom of PPA, it is important to determine which components of language use are most affected, how severely affected they are and what can be done to improve communication. A speech-language pathologist evaluates different aspects of language in detail and can make recommendations for strategies to improve communication. Family members should be included in the treatment sessions to educate them about how to facilitate communication.

Causes and risks

Frontotemporal degenerations are inherited in about a third of all cases. Genetic counseling and testing are available for individuals with a family history of frontotemporal degenerations. Family history is the only known risk factor for any of the frontotemporal degenerations.

Outcomes

Frontotemporal degenerations worsen, but speed of decline varies from person to person. Individuals living with FTD may experience muscle weakness and coordination problems for many years, often requiring use of a wheelchair or confining them bedridden. These muscle issues can cause problems with swallowing, chewing, moving and controlling bladder and/or bowel function. As a result of their vulnerable physical state, many individuals living with frontotemporal degenerations die from complications with skin, urinary tract and/or lung infections.

Treatment

No specific treatments exist for any of the frontotemporal degeneration disorders. However, medications can reduce agitation, irritability and/or depression, and help improve overall quality of life. Speech therapy may be beneficial to individuals with PPA, as it can focus directly on the language skills that are impaired.

Resources

Association for Frontotemporal Degeneration (AFTD)
theaftd.org
866.507.7222

Cure PSP
psp.org

National Aphasia Association
aphasia.org

TS-0091 | Updated June 2018

Parkinson's disease dementia

A topic in the Alzheimer's Association® series on understanding dementia.

About dementia
Dementia is a condition in which a person has significant difficulty with daily functioning because of problems with thinking and memory. Dementia is not a single disease; it's an overall term — like heart disease — that covers a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term dementia are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behavior, feelings and relationships.

Brain changes that cause dementia may be temporary, but they are most often permanent and worsen over time, leading to increasing disability and a shortened life span. Survival can vary widely, depending on such factors as the cause of the dementia, age at diagnosis and coexisting health conditions.

Parkinson's disease dementia
Parkinson's disease dementia is a decline in thinking and reasoning that develops in many people living with Parkinson's at least a year after diagnosis. The brain changes caused by Parkinson's disease begin in a region that plays a key role in movement, leading to early symptoms that include tremors and shakiness, muscle stiffness, a shuffling step, stooped posture, difficulty initiating movement and lack of facial expression. As brain changes caused by Parkinson's gradually spread, they often begin to affect mental functions, including memory and the ability to pay attention, make sound judgments and plan the steps needed to complete a task.

The key brain changes linked to Parkinson's disease and Parkinson's disease dementia are abnormal microscopic deposits composed chiefly of alpha-synuclein, a protein found widely in the brain with a normal function not yet known. The deposits are called "Lewy bodies" after Frederick H. Lewy, M.D., the neurologist who discovered them while working in Dr. Alois Alzheimer's laboratory during the early 1900s.

Lewy bodies are also found in several other brain disorders, including dementia with Lewy bodies (DLB). Evidence suggests that DLB, Parkinson's disease and Parkinson's disease dementia may be linked to the same underlying abnormalities in the brain processing of alpha-synuclein. Another complicating factor is that many people with both DLB and Parkinson's disease dementia also have plaques and tangles — hallmark brain changes linked to Alzheimer's disease.

Prevalence
Parkinson's disease is a fairly common neurological disorder in older adults, estimated to affect nearly 2 percent of those over age 65. The National Parkinson Foundation estimates

that 1 million Americans have Parkinson's disease. Recent studies following people with Parkinson's over the entire course of their illness estimate that 50 to 80 percent of those with the disease may experience dementia.

Symptoms
Commonly reported symptoms include changes in memory, concentration and judgment; trouble interpreting visual information; muffled speech; visual hallucinations; delusions, especially paranoid ideas; depression, irritability and anxiety; and sleep disturbances, including excessive daytime drowsiness and rapid eye movement (REM) sleep disorder.

Diagnosis
There is no single test — or combination of tests — that conclusively determines that a person has Parkinson's disease dementia. Guidelines for diagnosing Parkinson's disease dementia and DLB are:

- **The diagnosis is Parkinson's disease dementia when** a person is originally diagnosed with Parkinson's disease based on symptoms related to movement and dementia symptoms don't appear until a year later or more.
- **The diagnosis is DLB when** dementia symptoms consistent with DLB either develop first; are present along with symptoms related to movement; or appear within one year after movement symptoms.

Causes and risk factors
An estimated 50 to 80 percent of those with Parkinson's eventually experience dementia as their disease progresses. Some studies have reported that the average time from onset of Parkinson's to developing dementia is about 10 years.

Certain factors at the time of Parkinson's diagnosis may increase future dementia risk, including advanced age, greater severity of motor symptoms and mild cognitive impairment (MCI). Additional risk factors may include the presence of hallucinations in a person who doesn't yet have other dementia symptoms; excessive daytime sleepiness; and a Parkinson's symptom pattern known as postural instability and gait disturbance (PIGD), which includes "freezing" in mid-step, difficulty initiating movement, shuffling, problems with balancing and falling.

Outcomes
Because Parkinson's disease and Parkinson's disease dementia damage and destroy brain cells, both disorders worsen over time. Their speed of progression can vary widely.

Treatment
There are no treatments to slow or stop the brain cell damage caused by Parkinson's disease dementia. Current strategies focus on improving symptoms. If your treatment plan includes medications, it's important to work closely with your physician to identify the drugs that work best for you and the most effective doses.

- **Cholinesterase inhibitors** — drugs that are the current mainstay for treating cognitive changes in Alzheimer's — may help Parkinson's disease dementia symptoms, including visual hallucinations, sleep disturbances and changes in thinking and behavior.

- **Antipsychotics** — a drug category sometimes prescribed for behavioral symptoms of Alzheimer's — should be used with extreme caution because they may cause serious side effects in up to 50 percent of those with Parkinson's disease dementia or DLB. Side effects may include sudden changes in consciousness, impaired swallowing, acute confusion, episodes of delusions or hallucinations, or appearance or worsening of Parkinson's symptoms.

Treating movement symptoms in those with Parkinson's dementia can be challenging, because L-dopa — the chief treatment for Parkinson's movement symptoms — can sometimes aggravate hallucinations and confusion in those with Parkinson's dementia or DLB.

Depression is common in individuals with Parkinson's disease dementia and DLB, and may be treated with a type of antidepressant called selective serotonin reuptake inhibitors (SSRIs). REM disorder may be treated with clonazepam.

Additional resources

National Parkinson Foundation, Inc.
parkinson.org
800.473.4636

Michael J. Fox Foundation for Parkinson's Research
michaeljfox.org
800.708.7644

TS-0096 | Updated June 2016

LEWY BODY DEMENTIA IS…

A progressive brain disease and the second most common cause of neurodegenerative dementia after Alzheimer's disease. Lewy body dementia is a 'spectrum disorder,' meaning it can occur alone or in combination with Parkinson's disease, or co-exist with Alzheimer's disease.

LEWY BODY DEMENTIA IS NOT A RARE DISEASE…

It accounts for up to 20% of dementia cases in the U.S. — that's up to 1.3 million cases in the U.S. alone, with only 30%-50% of LBD cases being accurately diagnosed, even in dementia centers.

EARLY AND ACCURATE DIAGNOSIS IS IMPORTANT BECAUSE…

Antipsychotic drugs may cause **extreme adverse** reactions in those with LBD. Cholinesterase inhibitors may **improve** alertness and cognition and potentially reduce hallucinations and behavioral symptoms.

Lewy body dementias (LBD) include:

Parkinson's disease dementia (PDD) **dementia with Lewy bodies (DLB)**

Items in bold are included in DLB diagnostic criteria:

Dementia symptoms specific to Lewy body dementia:

- ***Fluctuating cognition***
- ***Neuroleptic sensitivity***

LBD Symptoms that resemble Alzheimer's:

- ***Progressive memory loss***
- Changes in mood and behavior
- Decreased judgment and insight
- Loss of initiative
- Disorientation re: time and place
- Difficulty with language and tasks

Dementia symptoms that resemble Parkinson's:

- ***Extrapyramidal signs***
- Muscle stiffness and rigidity
- Very slow movements, frozen stance
- Balancing difficulties, shuffling gait
- Tremors
- Stooped posture
- Blank facial expression
- Difficulty swallowing, weak voice
- Restless leg syndrome
- Repeated falls, fainting, myoclonus

Additional symptoms typical of Lewy body dementia:

- ***Visual hallucinations*** (also smell, sound, taste, touch)
- Transient/unexplained unresponsiveness
- Delusions, mood disorders
- Illusions
- Visuospatial impairment (depth perception, object orientation)
- ***Sleep disturbances, such as acting out vivid nightmares and dreams***
- Autonomic dysfunction (blood pressure fluctuations, constipation, incontinence, sexual dysfunction)

Clinical management is challenging because…

Antipsychotic drugs may cause worsening of confusion, Parkinsonism, heavy sedation, neuroleptic malignant syndrome.

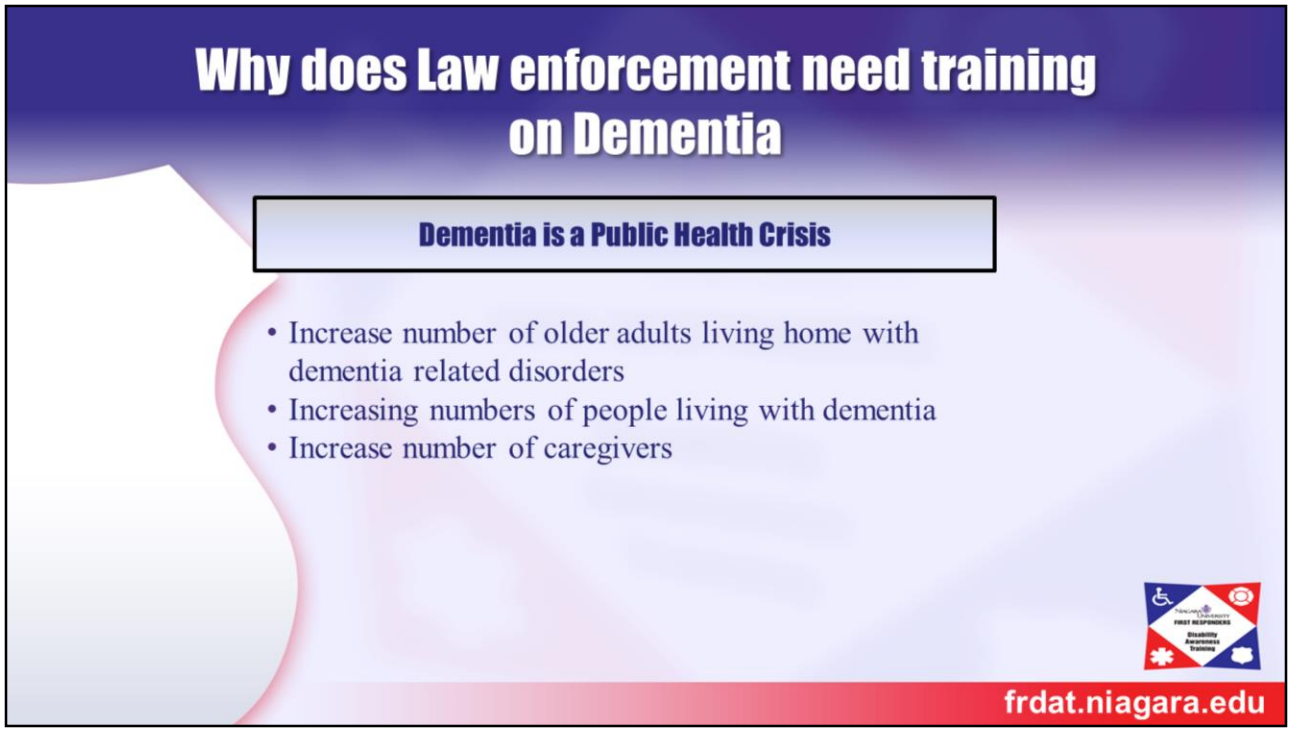
Benzodiazepines, anticholinergics, and some surgical anesthetics, antidepressants, and over-the-counter medications may cause sedation, motor impairment, or confusion.

Some medications for Parkinsonian symptoms may increase confusion, delusions, and hallucinations.

Lewy Body Dementia Association, Inc.
912 Killian Hill Rd., S.W.
Lilburn, GA 30047
Office: 404-935-6444
Fax: 480-422-5434
Caregiver Helpline: 800-LEWY-SOS (800-539-9767)
www.lbda.org

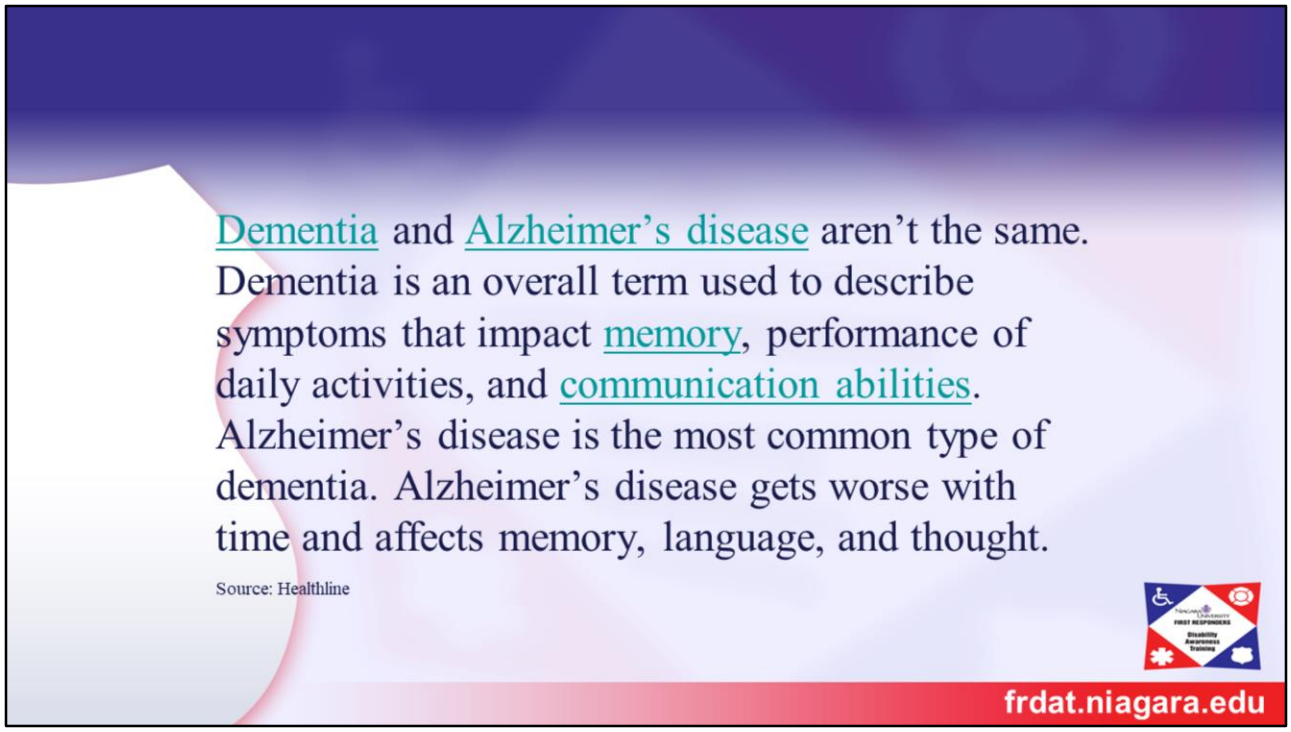
Handouts:

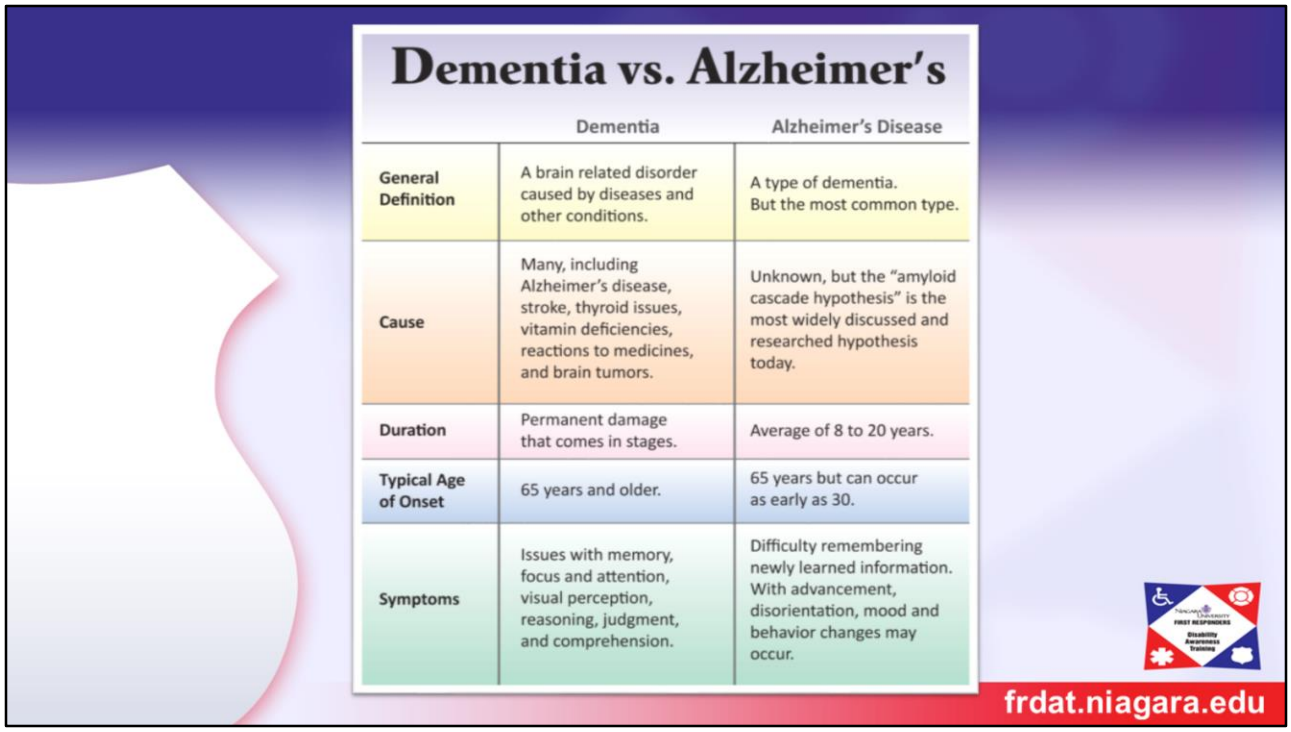
- Alzheimer's Disease and Other Dementias
- Vascular Dementia
- Frontotemporal Dementia
- Parkinson’s Disease
- Lewy Body Fact Sheet



The Project is so important because:

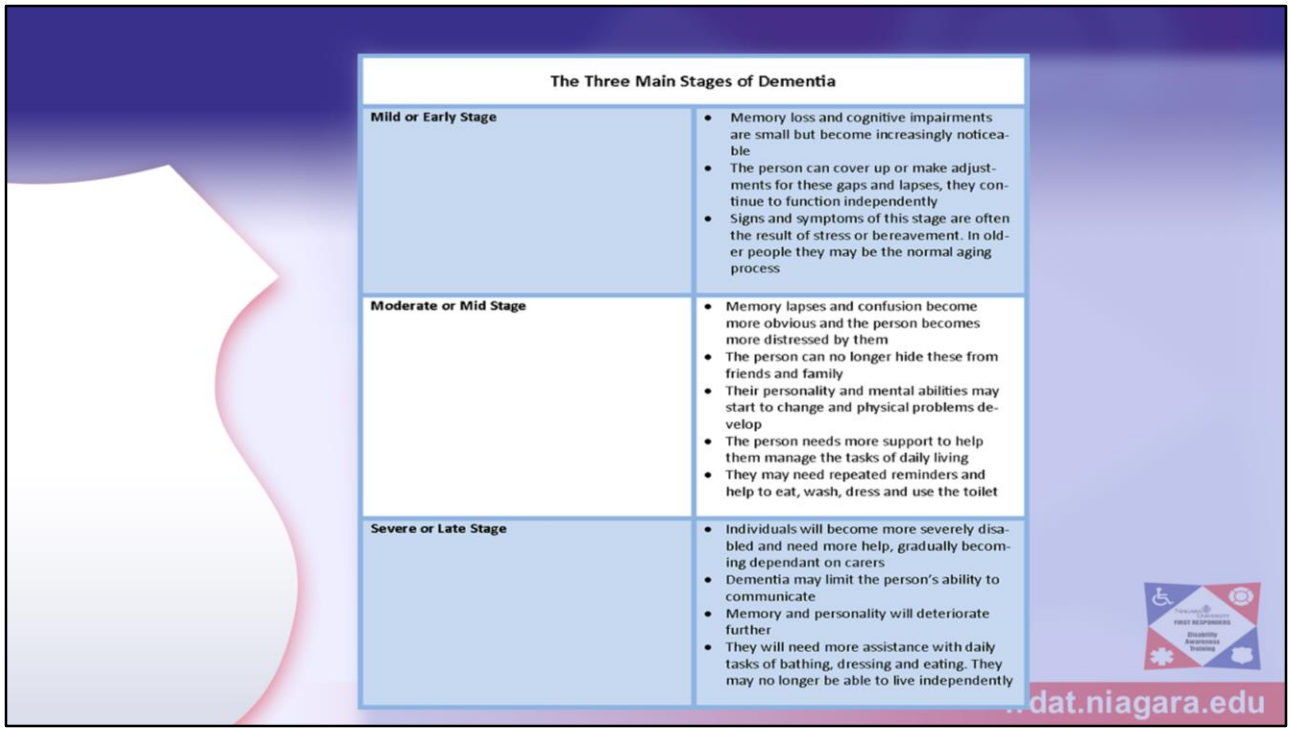
- Alzheimer's disease is a **public health crisis**, affecting entire families
  - Alzheimer's disease afflicts 5.7 million Americans. These numbers will double in less than 20 years and triple by 2050.
- **Caregivers** provide billions of dollars of unpaid care and many experience stress, burnout, and depression


Dementia and Alzheimer's disease aren't the same. Dementia is an overall term used to describe symptoms that impact memory, performance of daily activities, and communication abilities. Alzheimer's disease is the most common type of dementia. Alzheimer's disease gets worse with time and affects memory, language, and thought.
Source: Healthline
frdat.niagara.edu



- Dementia is a syndrome-a group of symptoms-that has a number of causes

- Alzheimer's disease is a degenerative brain disease and the most common cause of dementia

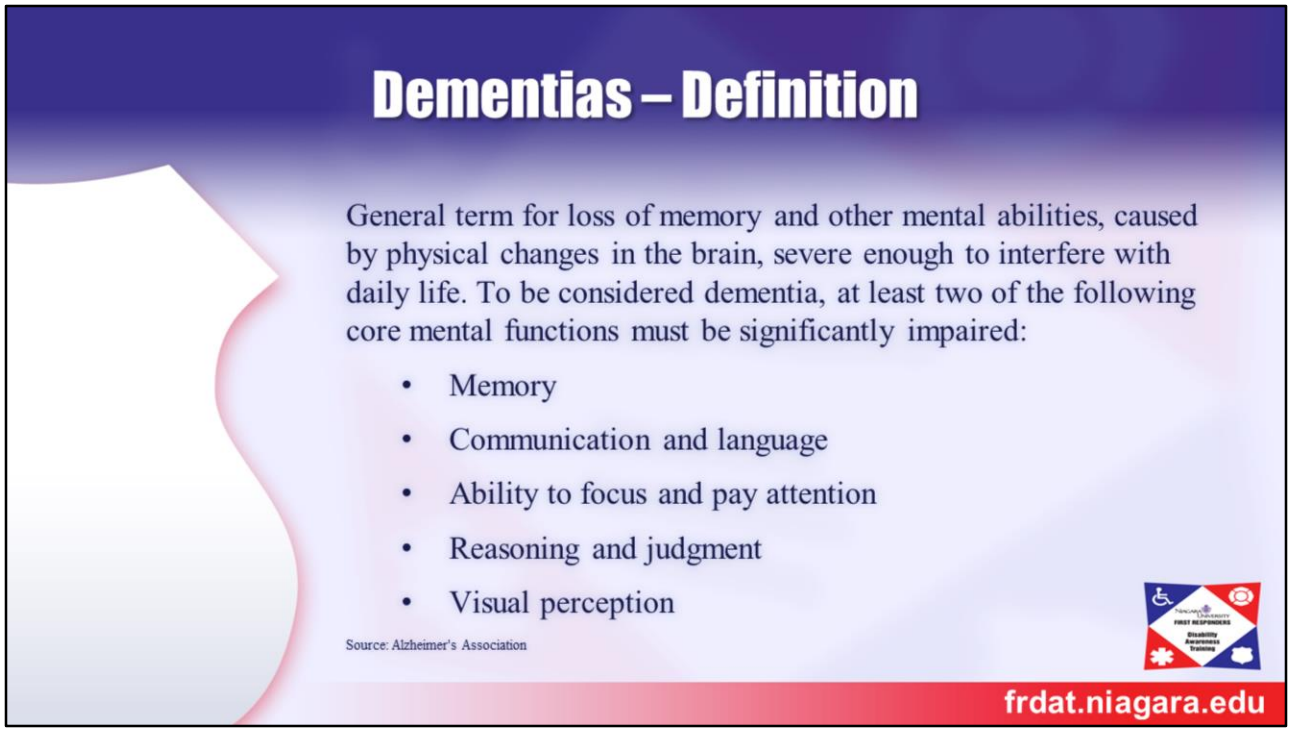

The Three Main Stages of Dementia
Mild or Early Stage
Memory loss and cognitive impairments are small but become increasingly noticeable
The person can cover up or make adjustments for these gaps and lapses, they continue to function independently
Signs and symptoms of this stage are often the result of stress or bereavement. In older people they may be the normal aging process
Moderate or Mid Stage
Memory lapses and confusion become more obvious and the person becomes more distressed by them
The person can no longer hide these from friends and family
Their personality and mental abilities may start to change and physical problems develop
The person needs more support to help them manage the tasks of daily living
They may need repeated reminders and help to eat, wash, dress and use the toilet
Severe or Late Stage
Individuals will become more severely disabled and need more help, gradually becoming dependant on carers
Dementia may limit the person's ability to communicate
Memory and personality will deteriorate further
They will need more assistance with daily tasks of bathing, dressing and eating. They may no longer be able to live independently
dat.niagara.edu

Dementia

A progressive and ultimately fatal collection of neurodegenerative diseases, which affect cognition and memory

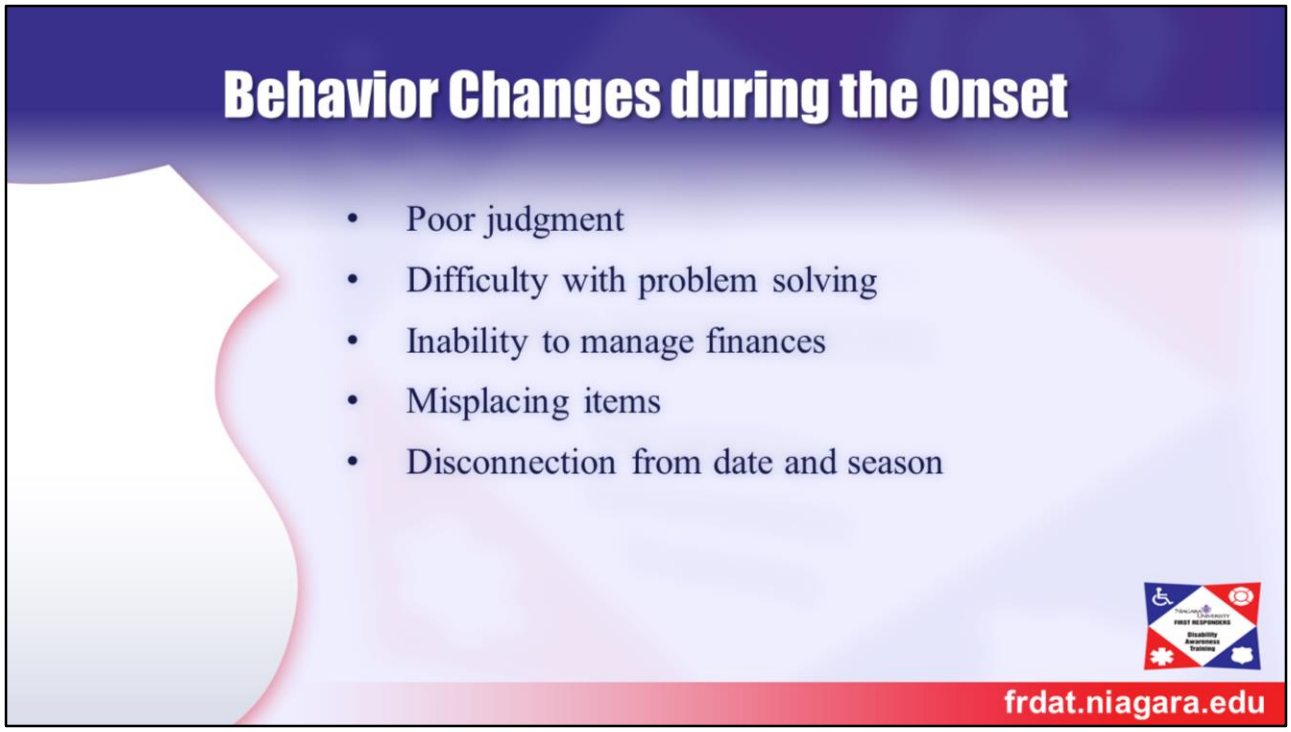
Over time it can cause changes in memory, thought, navigation, language, behavior, mood and personality

frdat.niagara.edu

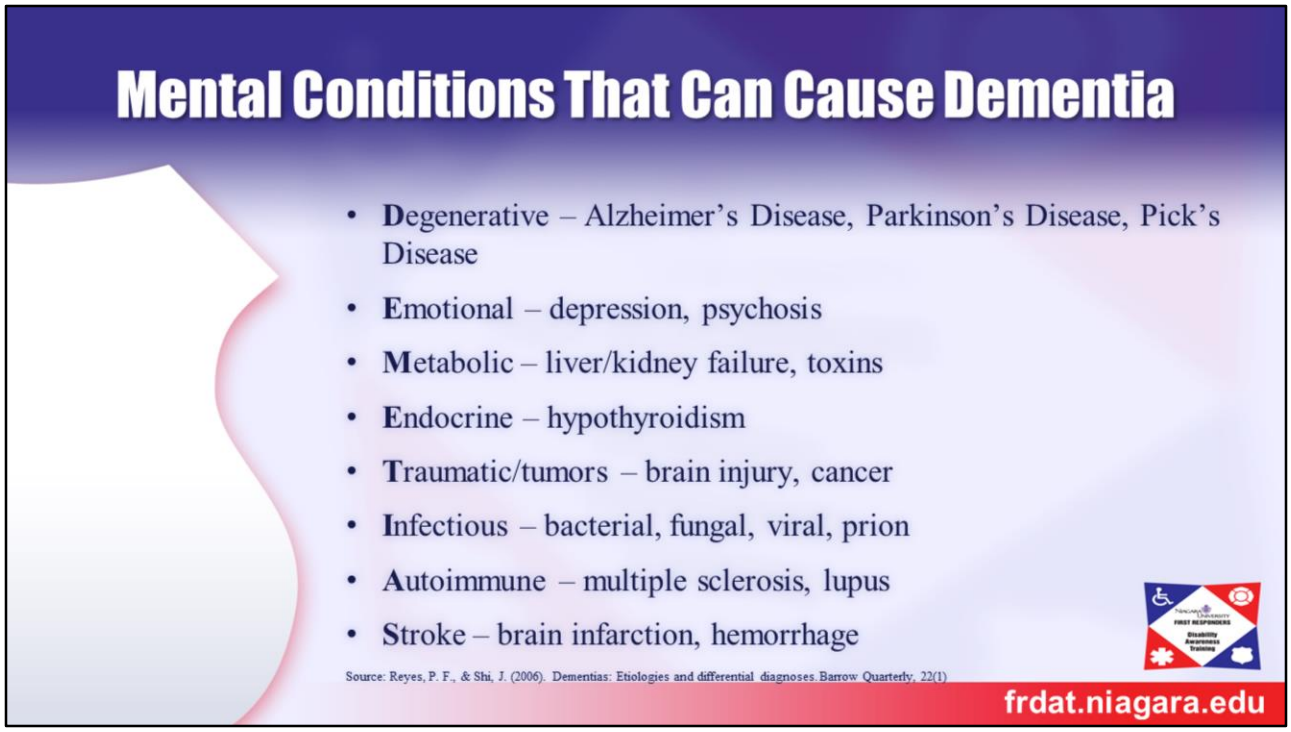


CLICK AND READ 5 BULLETS

- Memory: ability to learn and recall new information.
- Communication and language: ability to write or speak or to understand written or spoken words. What once came naturally is now compromised.
- Reason and judgment: ability to plan, reason, solve problems, and focus on tasks.
- Visual perception: ability to understand and use symbols, maps, etc., and the brain's ability to translate visual signals into a correct impression of where objects are in space.
- Depth perception is also compromised – for instance, a black floor tile is viewed as a bottomless pit.



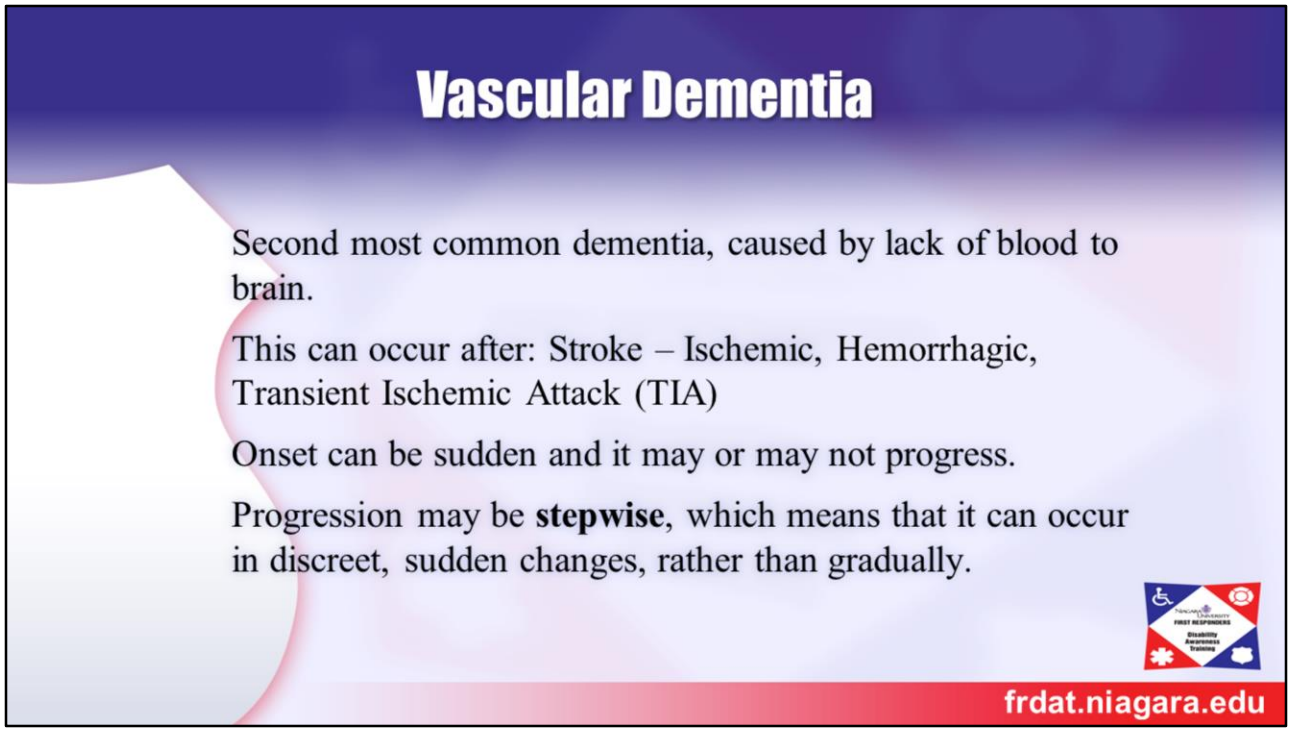
- Discuss how these behavior changes may present to an officer



- The type on the left is how dementia occurs with it's most common disabling condition on the right.
- State each type of dementia, along with it's corresponding example: Degenerative – Alzheimer's Disease.

CLICK AND READ 8 BULLETS

- Officers are most likely to encounter people with Alzheimer's Disease, stroke survivors, and those who have had head injuries.



CLICK AND READ SLIDE

- According to the National Institute of Health, more than 700,000 people a year have strokes, with two thirds survive and need rehabilitation
- Ischemic means when a blood vessel in the brain is blocked, often by cholesterol
- Hemorrhagic is when a blood vessel ruptures

Intracerebral hemorrhage

- most common type of hemorrhagic stroke. It occurs when an artery in the brain bursts, flooding the surrounding tissue with blood.

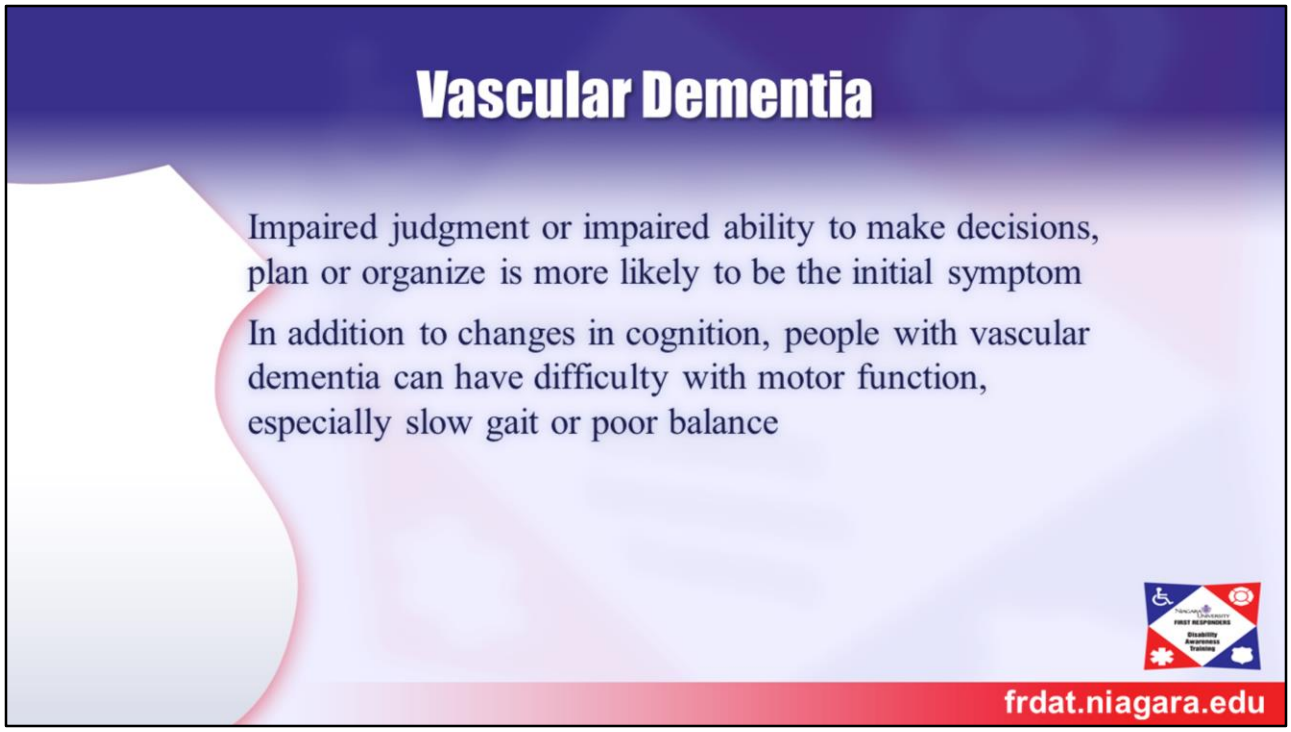
Subarachnoid hemorrhage

- less common type of hemorrhagic stroke. It refers to bleeding in the area between the brain and the thin tissues that cover it.
- TIA (transient ischemic attack) “mini” stroke; starts just like a

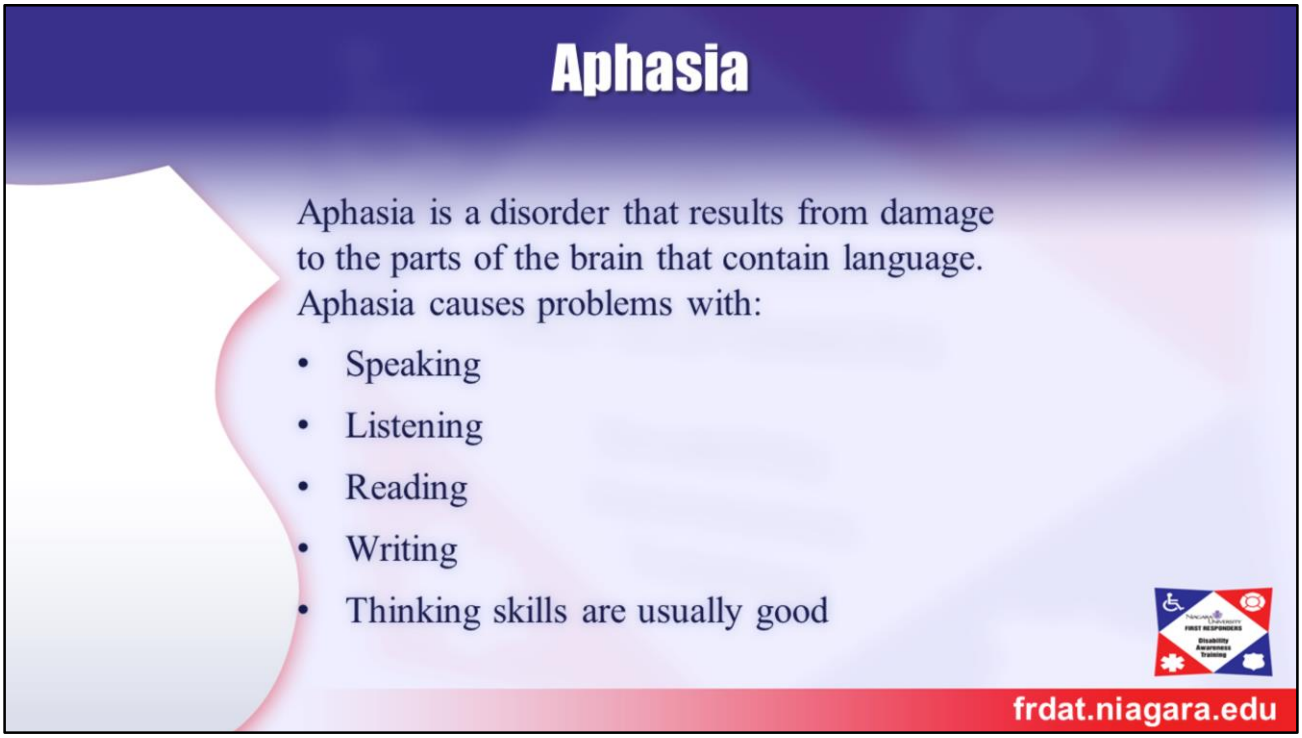
stroke but then resolves leaving no noticeable symptoms or deficits. Precursor to larger stroke

- People who have strokes frequently have memory problems; the specifics are different for each individual, as each of us is different
- Men are at a higher risk of stroke than women
- People from certain ethnic groups are more likely to develop vascular dementia than others.
- Commonly, however, one may have difficulty with the following:
  - Verbal memory – memory of names, stories and information having to do with words. You may be unable to remember and retrieve information.
  - Visual memory – memory of faces, shapes, routes and things you see. You may have trouble learning new information or skills.

- After a stroke, one of the most common thinking problems is trouble with communication.



- Brain changes from vascular dementia are found in about 40% of brains from individuals with dementia
- About 10% of brains from individuals with dementia show evidence of vascular dementia alone.
- Occurs most commonly from blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain

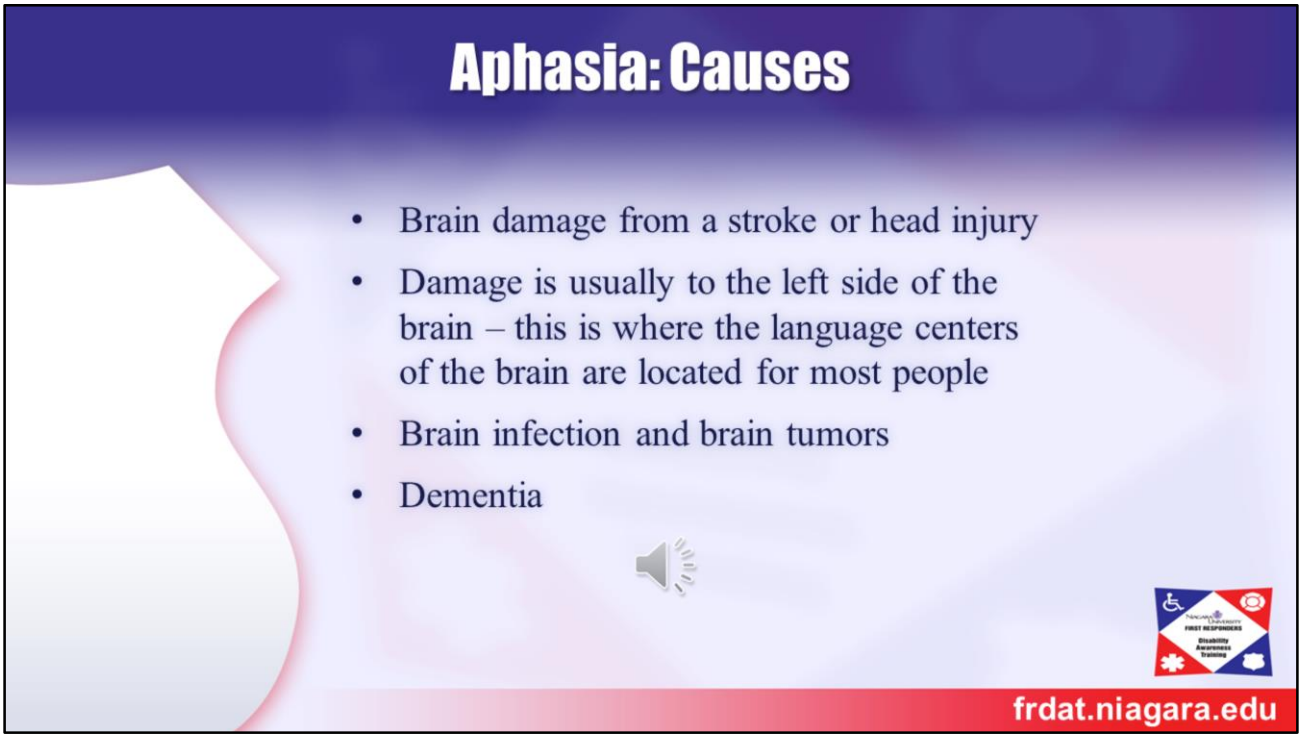


CLICK AND READ 5 BULLETS

- About one million people in the United States have aphasia, which is the a partial or total loss of ability to talk, understand what people say, read or write.

- It may affect only one aspect of language. For example, you may be unable to remember the names of objects or put words together into sentences. More often, many aspects are affected at the same time.

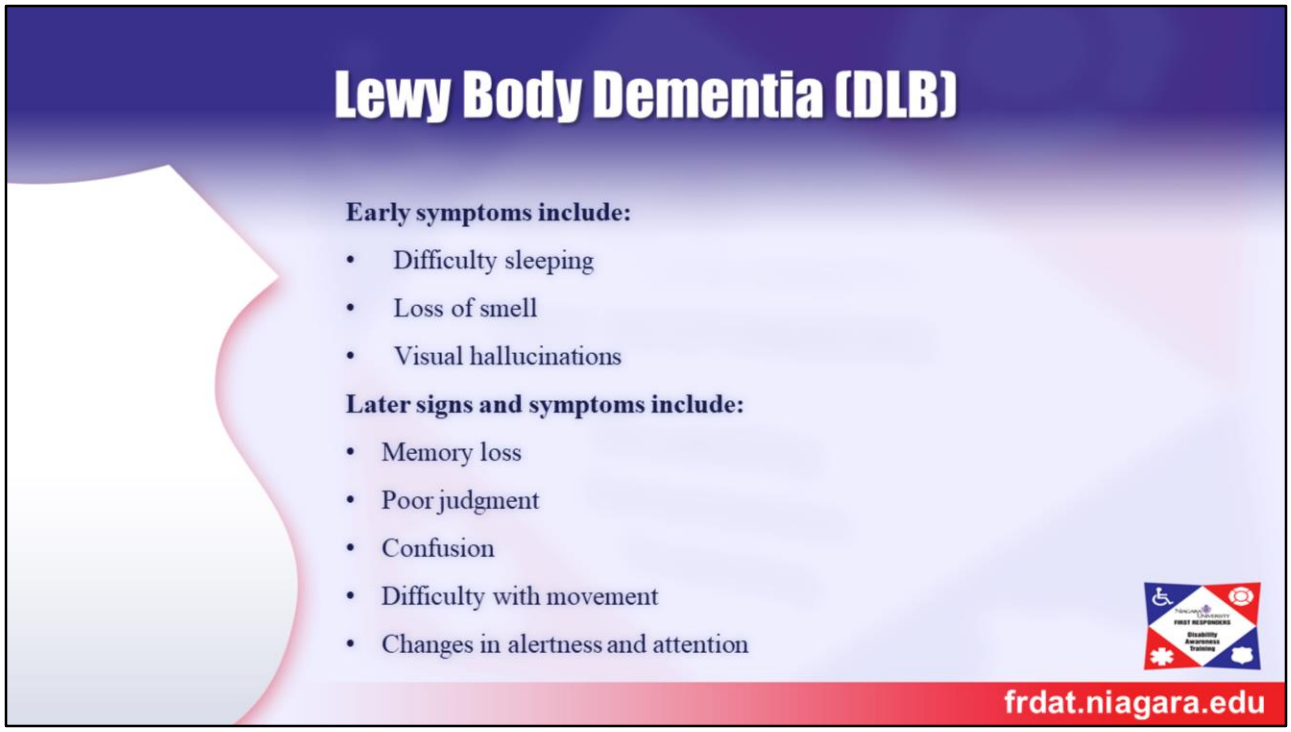
CLICK AND READ 5 BULLETS



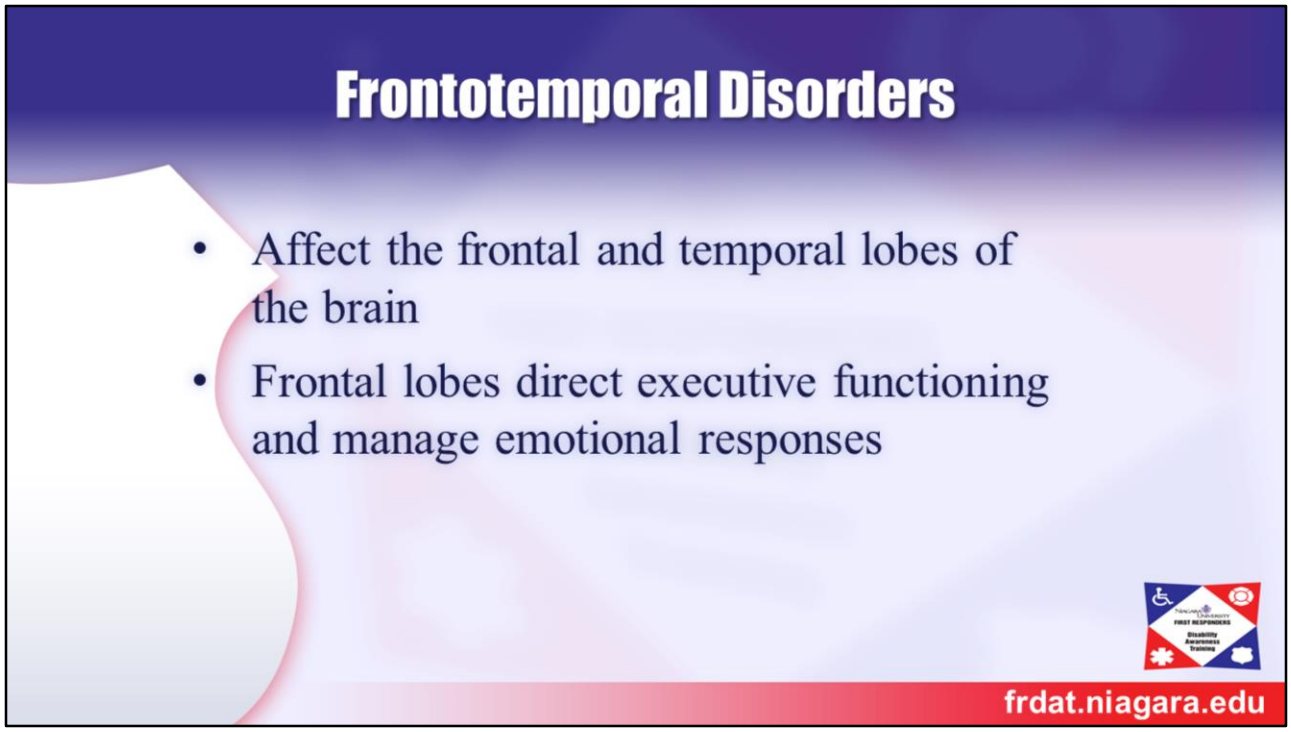
CLICK AND READ 4 BULLETS

CLICK ON AUDIO

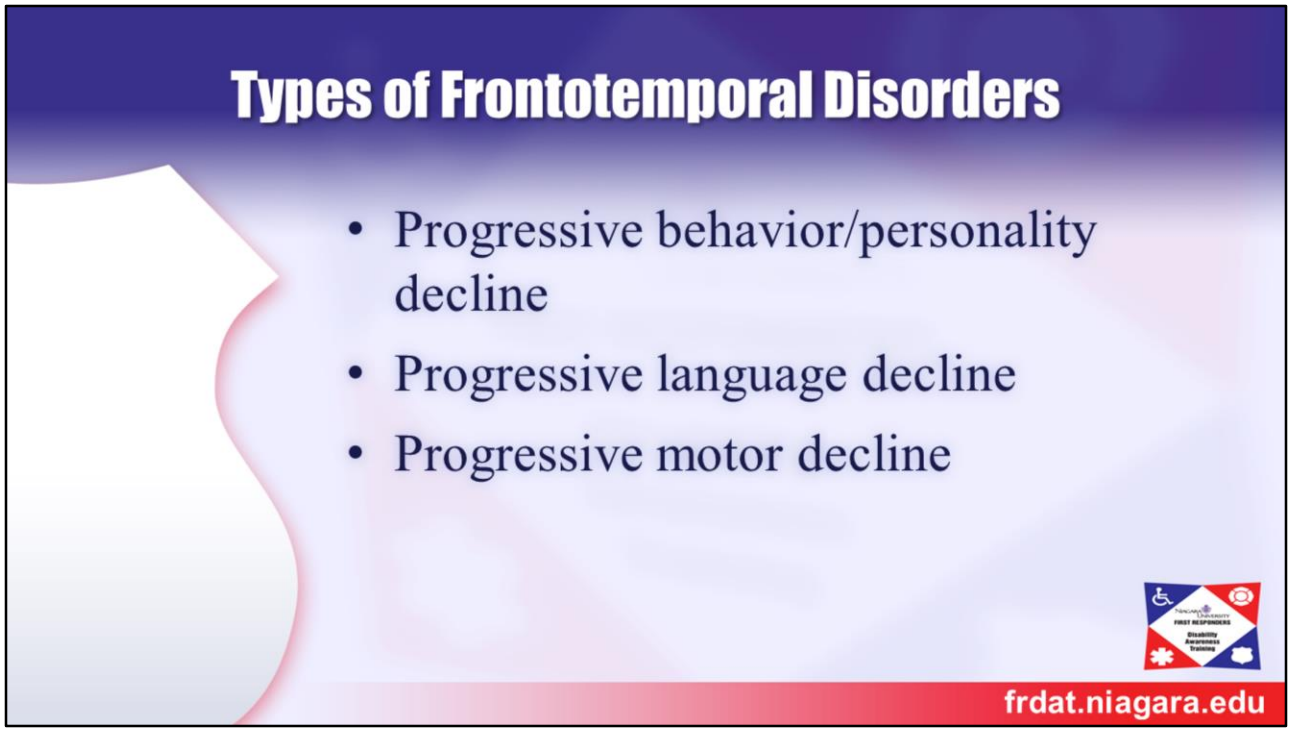
- Note the pauses, lack of sentence structure, uncertainty
- He would present with no physical indications he has a disability
- While the reason for his aphasia is stroke, it would present similarly for someone with dementia



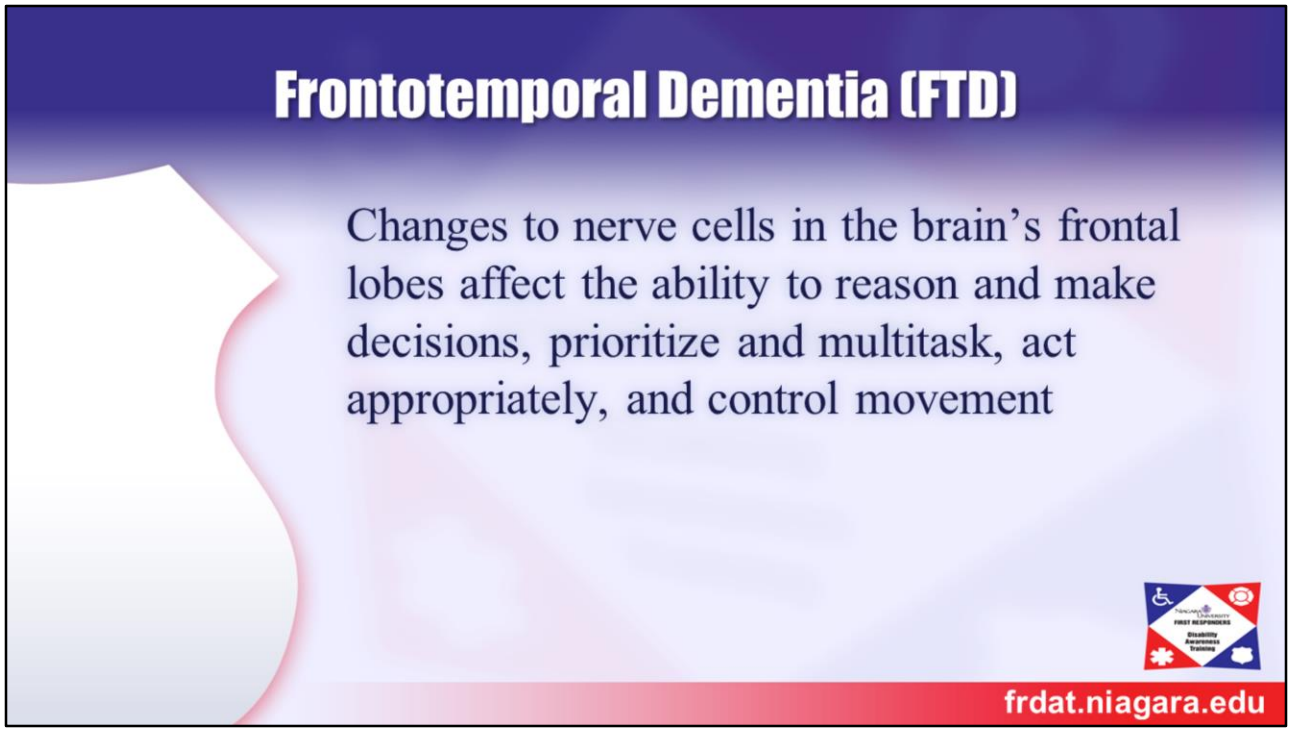
- One of the most common forms of dementia, affecting about 1.3M Americans
- Symptoms can be evident for up to 10 years before the more involved problems such as movement are evident
- Movement problems will look similar to Parkinson's Disease
- Given the variations in presentation and onset of symptoms, it can be very difficult to diagnose
- There is no cure
- Dementia with Lewy Bodies and Lewy Body Dementia are used interchangeably.



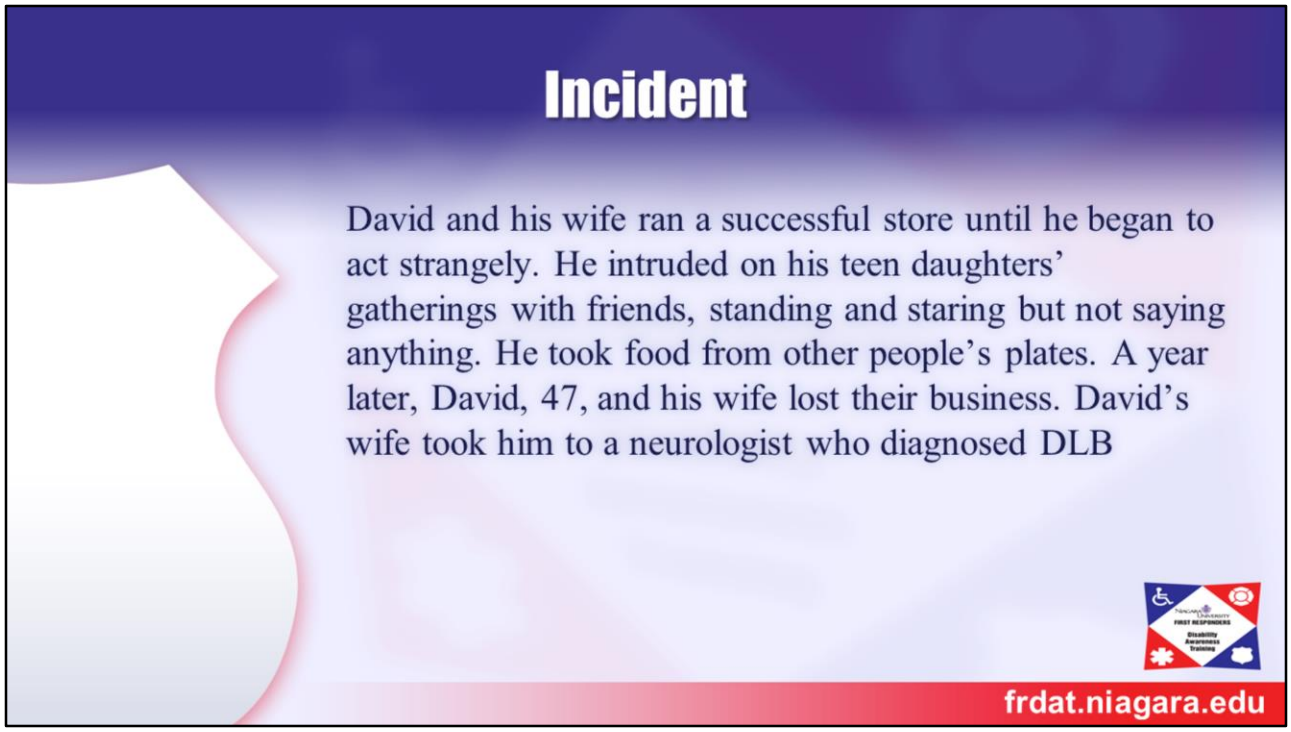
- Executive Functioning includes:
- Planning and Sequencing; thinking through which steps come first, second, third, so on)
- Prioritizing; doing some important activities first and less important last)
- Multitasking; shifting from activity to another as needed
- Monitoring and correcting errors



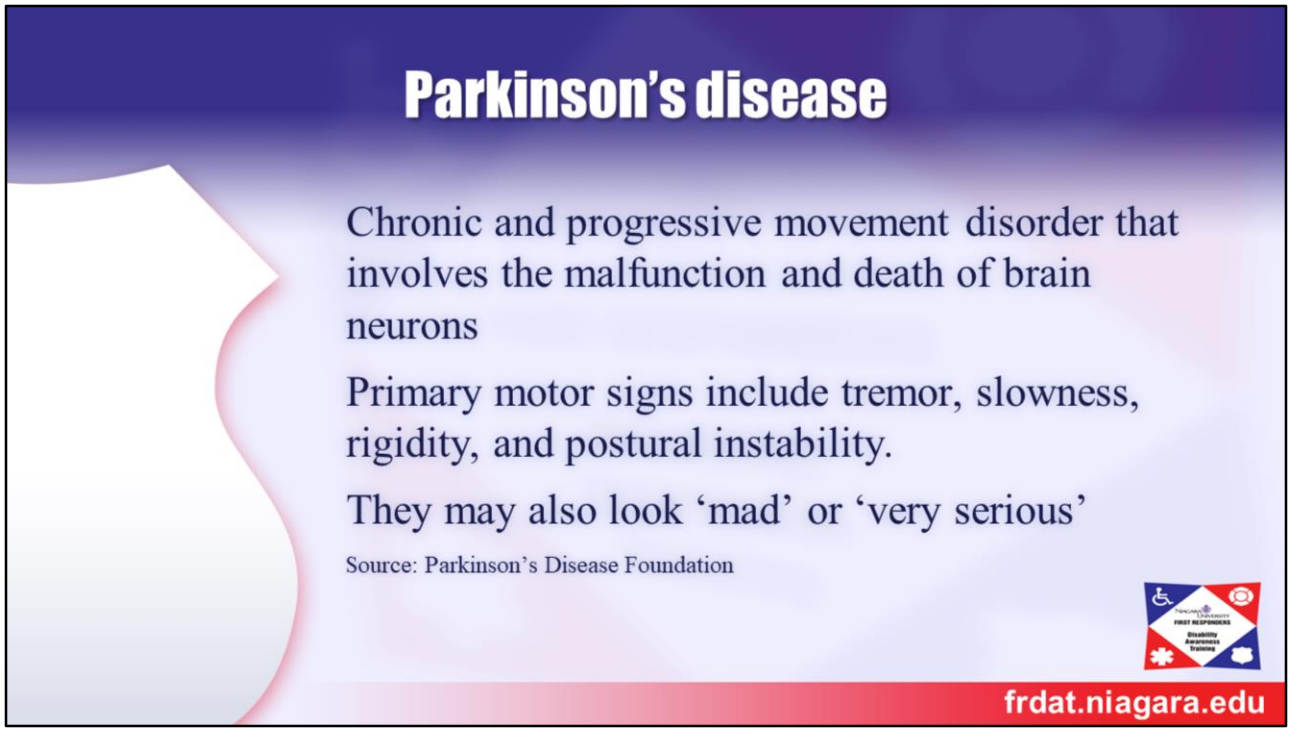
- Progressive behavior/personality decline is characterized by changes in personality, behavior, emotions, and judgment. This indicated dementia.
- Progressive language decline is marked by early changes in language ability, including speaking, understanding, reading, and writing. This is also called primary progressive aphasia
- Reflect on aphasia slides
- Progressive motor decline is characterized by various difficulties with physical movement, shaking, difficulty walking, frequent falls, and poor coordination. This is indicators of Lou Gehrig's Disease or Amyotrophic lateral sclerosis (ALS)
- Pick's Disease is another dementia resulting from this disorder



- Some people decline rapidly over 2-3 years while others can live 10 years (or longer)



- He did not realize how embarrassed his daughter and her friends were
- He was misdiagnosed as being clinically depressed.



- Early (recognizable) symptoms include loss of sense of smell, constipation, mood and sleep disorders, and low blood pressure when standing up.
- Some of the dying neurons produce dopamine. As it progresses, the decrease in dopamine leaves a person unable to control movement normally
- Sleep can be very difficult
- Average age of onset is 60 y/o
- There is no cure and it is not fatal
- Approximately 1M Americans live with PD


MJ FOX video
frdat.niagara.edu

Alzheimer's Disease

Objectives:

- How it affects individuals and proper response
- Defining Alzheimer's disease
- Identifying challenges posed to law enforcement
- Alzheimer's Disease progression
- Challenges to a caregiver

Main points: Alzheimer's disease accounts for 70% of dementia and is a leading cause of death amongst seniors. People with dementia may be confused and not be aware of time, place, or surroundings, even though it was once routine. An individual with memory loss will pose extreme challenges to an officer responding to a call.

Content:

- PowerPoint: 24 pages
- Videos:
    - Alzheimer's Association Facts Clip
    - Officer Tim Sutton
- Handouts:
    - Alzheimer's Disease

Resources:

- Alzheimer's Association: Phone: 1-800-272-3900: Website: www.alz.org:

- Huntington's Disease Society of America: Phone: 212-242-1968
- Alzheimer's Association of Missouri: Phone: 1.800.272.3900: Website: http://www.alz.org/greatermissouri/

Alzheimer's Disease

Alzheimer's (AHLZ-high-merz) is a disease of the brain. It destroys brain cells, causing problems with memory, thinking and behavior. It is the most common form of dementia.

It is estimated that there are as many as 5.4 million Americans living with Alzheimer's. This includes 5.2 million people age 65 and over and 200,000 people under age 65 with younger-onset Alzheimer's disease. The number of Americans with Alzheimer's disease and other dementias will grow each year as the proportion of the U.S. population that is over age 65 continues to increase. The number will escalate rapidly in coming years as the baby boom generation ages.

Alzheimer's is not a typical part of aging; it gets worse over time and it is fatal. Today it is the sixth-leading cause of death in the United States. There is currently no cure for Alzheimer's, but new treatments are on the horizon as a result of accelerating insight into the biology of the disease. Research has also shown that effective care and support can improve quality of life for individuals and their caregivers over the course of the disease from diagnosis to the end of life.

10 Warning Signs of Alzheimer's Disease©
The Alzheimer's Association has developed a checklist of common symptoms to help recognize the warning signs of Alzheimer's disease.

1. Memory changes that disrupt daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion to time and place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

If you or someone you know is experiencing these symptoms, consult a doctor. Every individual may experience one or more of these in different degrees. If you notice any of them, please see a doctor. Early and accurate diagnosis of Alzheimer's disease or other dementias is an important step to getting the right treatment, care and support.

Causes of Alzheimer's disease
In the vast majority of cases, the cause of Alzheimer's disease remains unknown. Most experts agree that Alzheimer's, like other common, chronic conditions, likely develops as a result of multiple factors rather than a single cause. Age is the greatest risk factor for Alzheimer's. Most Americans with Alzheimer's disease are age 65 or older.

A small percentage of Alzheimer cases is caused by rare, genetic variations found in a few hundred families worldwide. In these inherited forms of Alzheimer's, the disease tends to strike

younger individuals. When Alzheimer's is first recognized in a person under age 65, this is referred to as "younger-onset Alzheimer's."

How Alzheimer's disease affects the brain
Scientists believe that whatever triggers Alzheimer's begins to damage the brain years before symptoms appear. When symptoms emerge, nerve cells that process, store and retrieve information have already begun to degenerate and die.

Scientists regard two abnormal microscopic structures called "plaques" and "tangles" as the hallmarks of Alzheimer's disease. Amyloid plaques (AM-uh-loyd plaks) are clumps of protein fragments that accumulate between the brain's nerve cells. Tangles are twisted strands of another protein that form inside brain cells. Scientists have not yet determined the exact role that plaques and tangles may play. To learn more about how Alzheimer's affects the brain, see our online Brain Tour: www.alz.org/braintour

Diagnosing Alzheimer's disease
Experts estimate that a doctor experienced in diagnosing Alzheimer's can make a diagnosis with more than 90 percent accuracy. Because there is no single test for Alzheimer's, diagnosis usually involves a thorough medical history and physical examination as well as tests to assess memory and the overall function of the mind and nervous system. The doctor may ask a family member or close friend about any noticeable change in the individual's memory or thinking skills.

Most diagnostic uncertainty arises from occasional difficulty distinguishing Alzheimer's disease from a related dementia. Dementia is a general term for a group of brain disorders that affect memory, judgment, personality and other mental functions. Alzheimer's disease is the most common type of dementia, accounting for 60 to 80 percent of cases.

Vascular dementia, another common form, results from reduced blood flow to the brain's nerve cells. In some cases, Alzheimer's disease and vascular dementia can occur together in a condition called "mixed dementia." Other causes of dementia include frontotemporal dementia, dementia with Lewy bodies, Creutzfeldt-Jakob disease and Parkinson's disease. Learn more about related dementias: www.alz.org/relateddementias.

One important goal of the diagnostic workup is to determine whether symptoms may be due to a condition other than Alzheimer's. Depression, medication side effects, certain thyroid conditions, excess use of alcohol and nutritional imbalances are all potentially treatable disorders that may sometimes impair memory or other mental functions. Even if the diagnosis is Alzheimer's disease, timely identification enables individuals to take an active role in treatment decisions and planning for the future.

Treatment and prevention of Alzheimer's disease
Medications approved by the U.S. Food and Drug Administration (FDA) may temporarily delay memory decline and treat Alzheimer symptoms for some individuals, but none of the currently approved drugs is known to stop or prevent the disease. Certain drugs approved to treat other illnesses may sometimes help with the emotional and behavioral symptoms of Alzheimer's.

One important part of treatment is supportive care that helps individuals and their families come to terms with the diagnosis; obtain information and advice about treatment options; and maximize quality of life through the course of the illness.

Many scientists consider the emerging field of prevention one of the most exciting recent developments in dementia research. Some of the most exciting preliminary evidence suggests that strategies for general healthy aging may also help reduce the risk of developing Alzheimer's. These measures include controlling blood pressure, weight and cholesterol levels; exercising both body and mind; eating a brain-healthy diet that is low in fat and includes fruits and vegetables; and staying socially active.

Impact on people living with Alzheimer's disease
Due to changes in the brain, people with Alzheimer's will eventually lose sense of who they are and the ability to care for themselves. The disease affects independence, relationships and the ability to express oneself.

Younger individuals with the disease can also face other issues. If they are employed, they may have to reduce work hours or quit, leaving a gap in the family income. Kids may still be living at home. Insurance and other benefits may be more difficult to get to help pay for care.

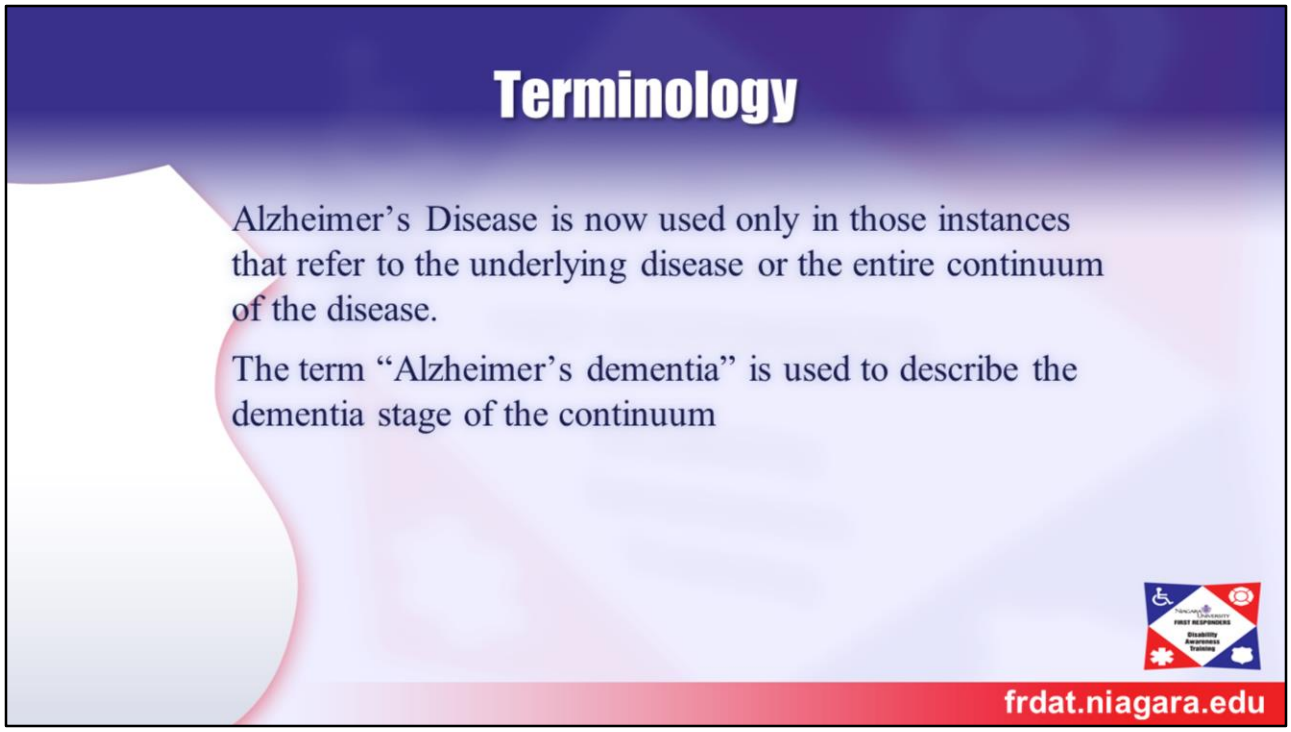
Impact on caregivers
Millions of family members are currently facing the enormous physical, emotional and financial impact of caring for a loved one. Seventy percent of people with Alzheimer's live at home, where family and friends provide most of their care and pay for it out of their own pockets.

Impact on society
Alzheimer's takes an enormous toll on society. Total payments from all sources for health and long-term care services for people with Alzheimer's and dementia will amount to $183 billion. People with Alzheimer's and other dementias are high users of healthcare, long-term care and hospice. Total payments for these types of care from all services, including Medicare and Medicaid, are nearly three times higher for older people with Alzheimer's and other dementias than for other older people.

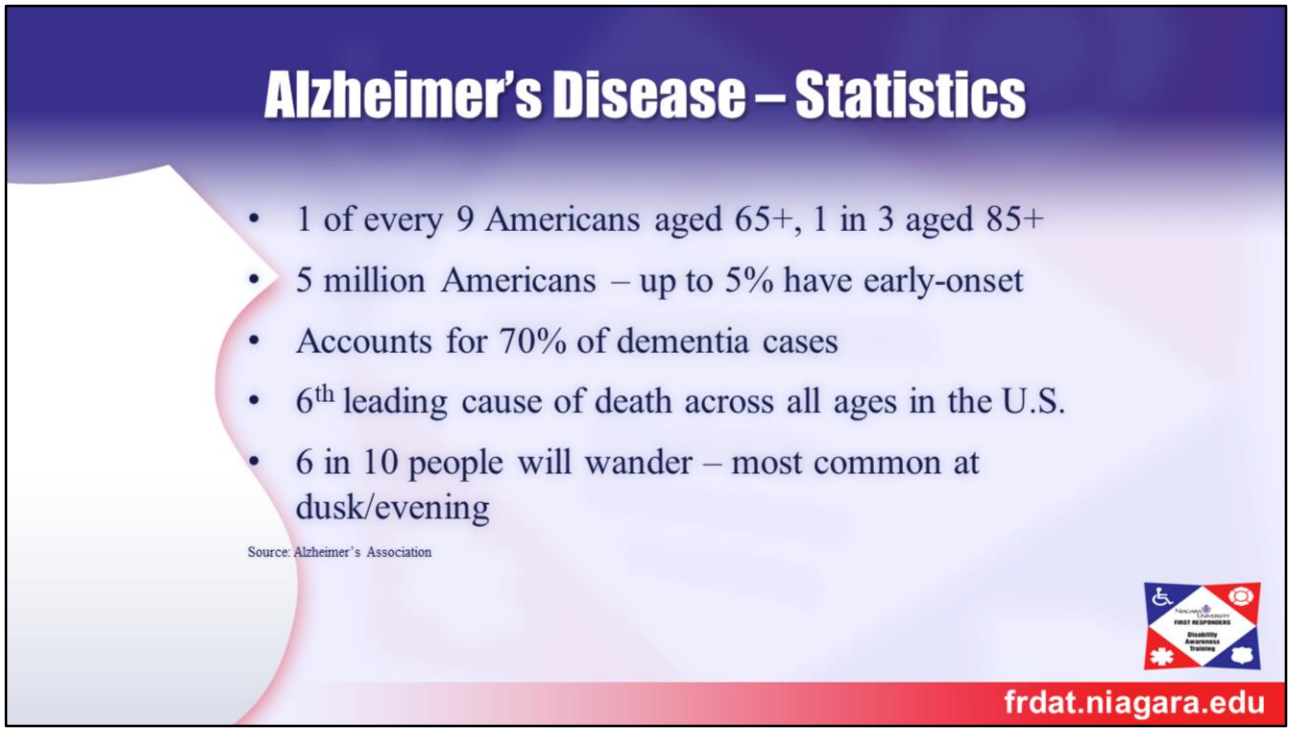
The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Updated March 2011

Handouts:
1. Alzheimer’s Disease

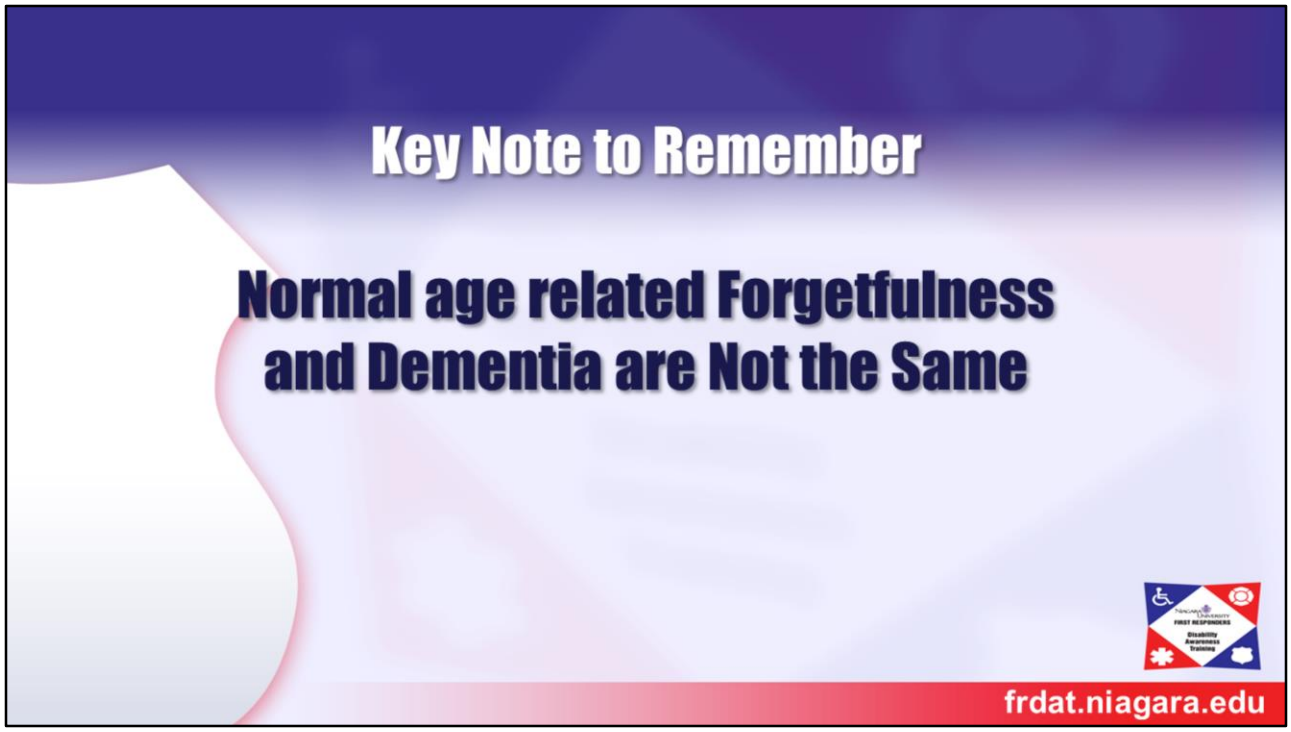


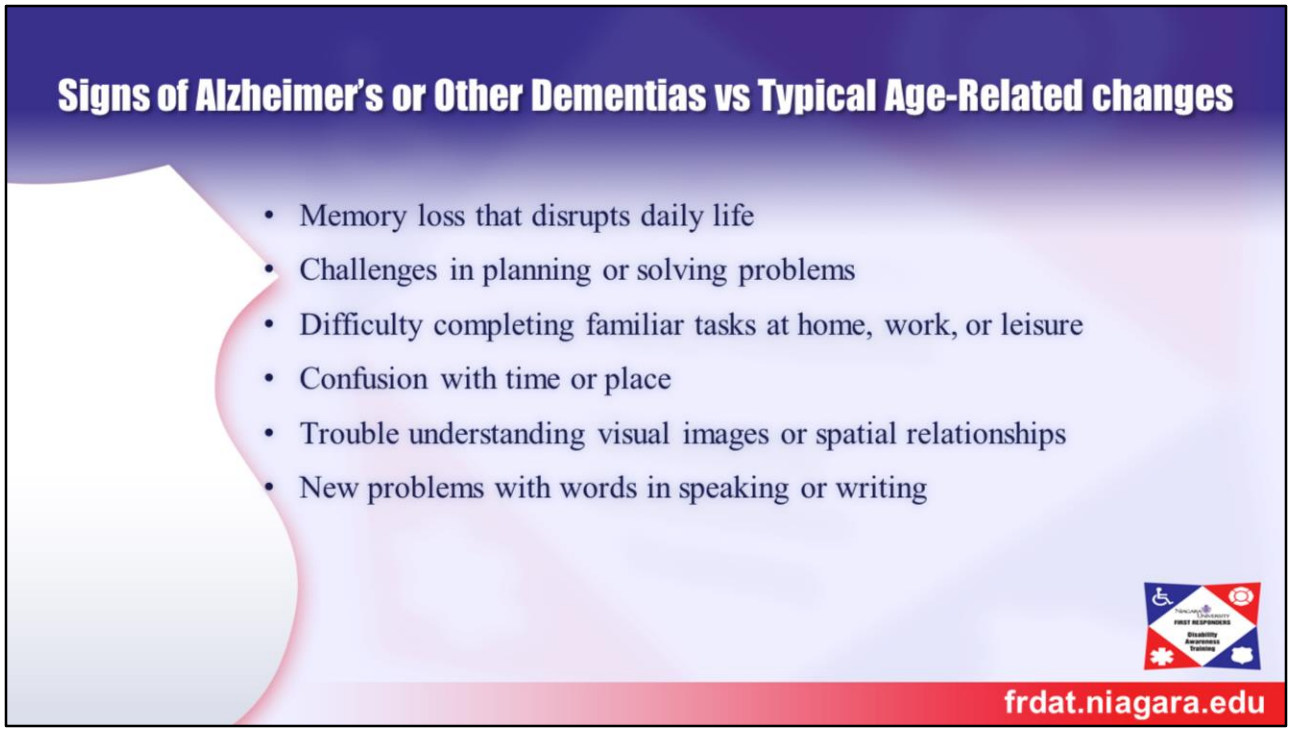
- The 2018 Alzheimer's Disease Facts and Figures notes a change in the terminology
- Alzheimer's is a dementia
- Onset may begin 20 years before it is evident



CLICK AND READ 5 BULLETS

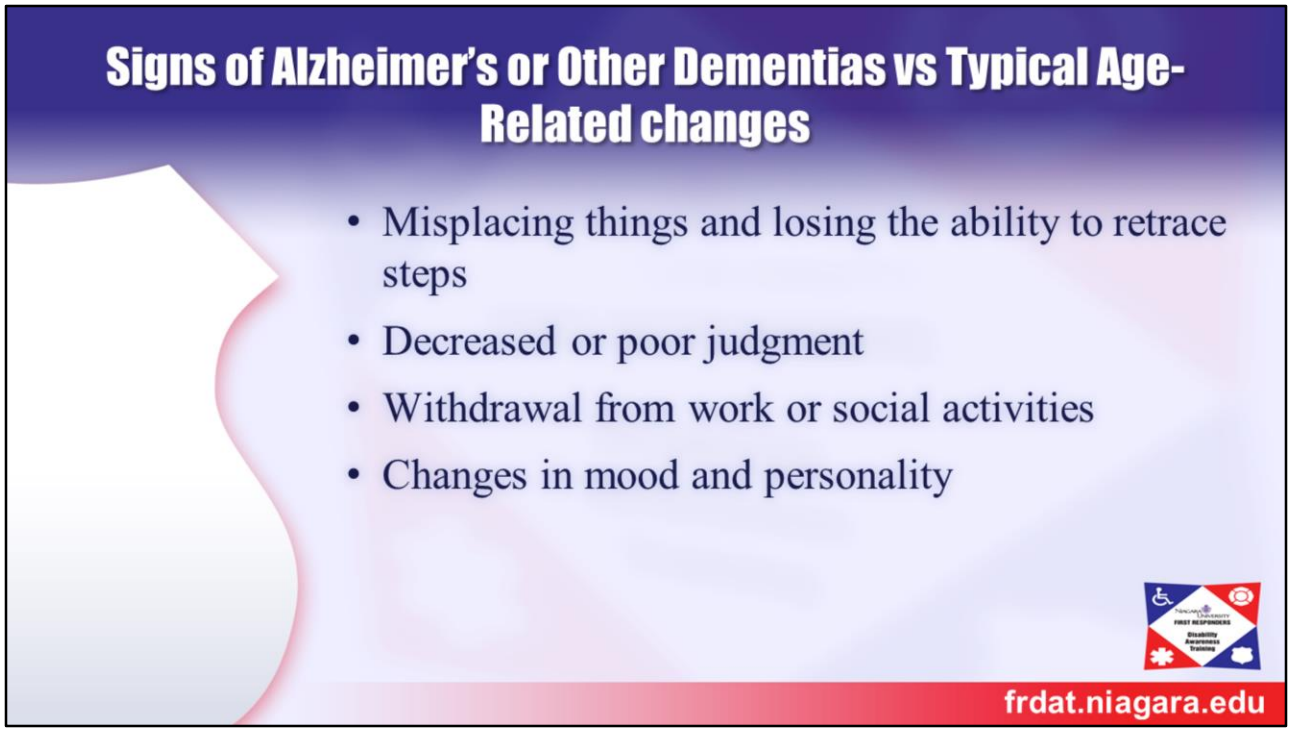
- Early-onset means it happens at an age prior to 65 years old.
- By far, as numbers indicate, it is the leading cause of dementia.
- People with Down Syndrome have a high incidence of comorbidity. Depending on who you talk to, approximately 70% of individuals with DS will have Alzheimer's.
- While noted it is the 6th leading cause across all ages, it is the 5th leading cause of death for those aged 65 and older.
- Wandering often happens at dusk/evening, commonly referred to as "sundowning."


Key Note to Remember
Normal age related Forgetfulness and Dementia are Not the Same
frdat.niagara.edu



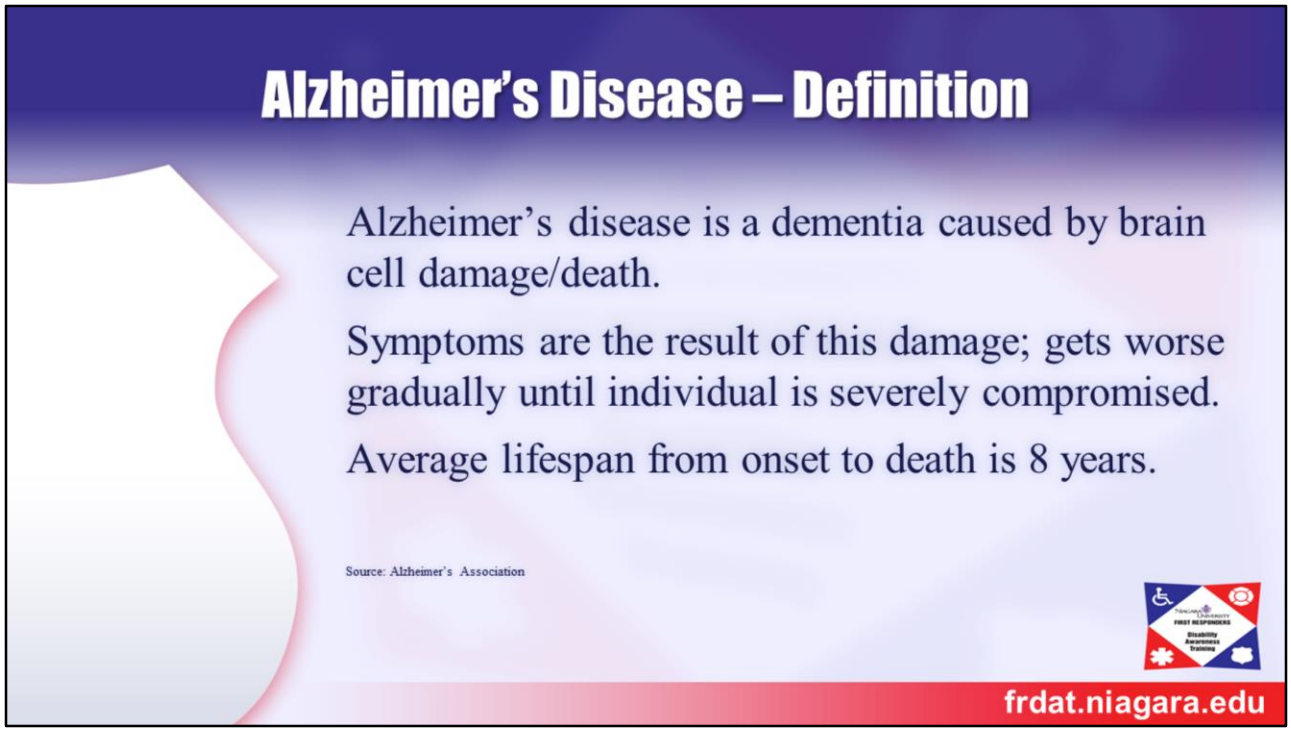
Versus Typical Age-Related Changes:

- Sometimes forgetting names to appointments, but remembering later
- Making occasional errors when balancing a checkbook
- Occasionally needing help to use the settings on a microwave or record a TV show
- Getting confused about the day of the week but remembering later
- Vision changes related to cataracts, glaucoma, or age-related macular degeneration
- Sometimes having trouble finding the right word



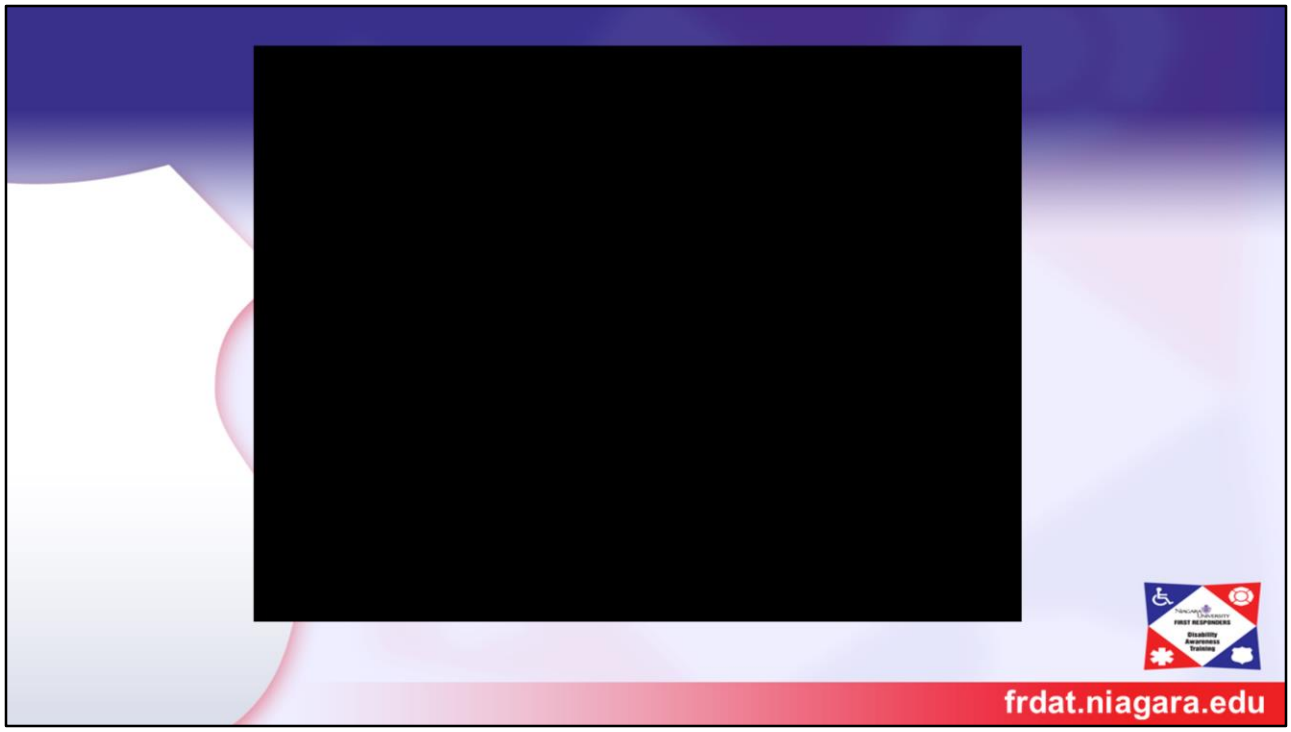
Versus Age-Related changes

- Misplacing things from time to time and retracing steps to find them
- Making a bad decision once in awhile
- Sometimes feeling weary of work, family and social obligations
- Developing very specific ways of doing things and becoming irritable when routine is disrupted.



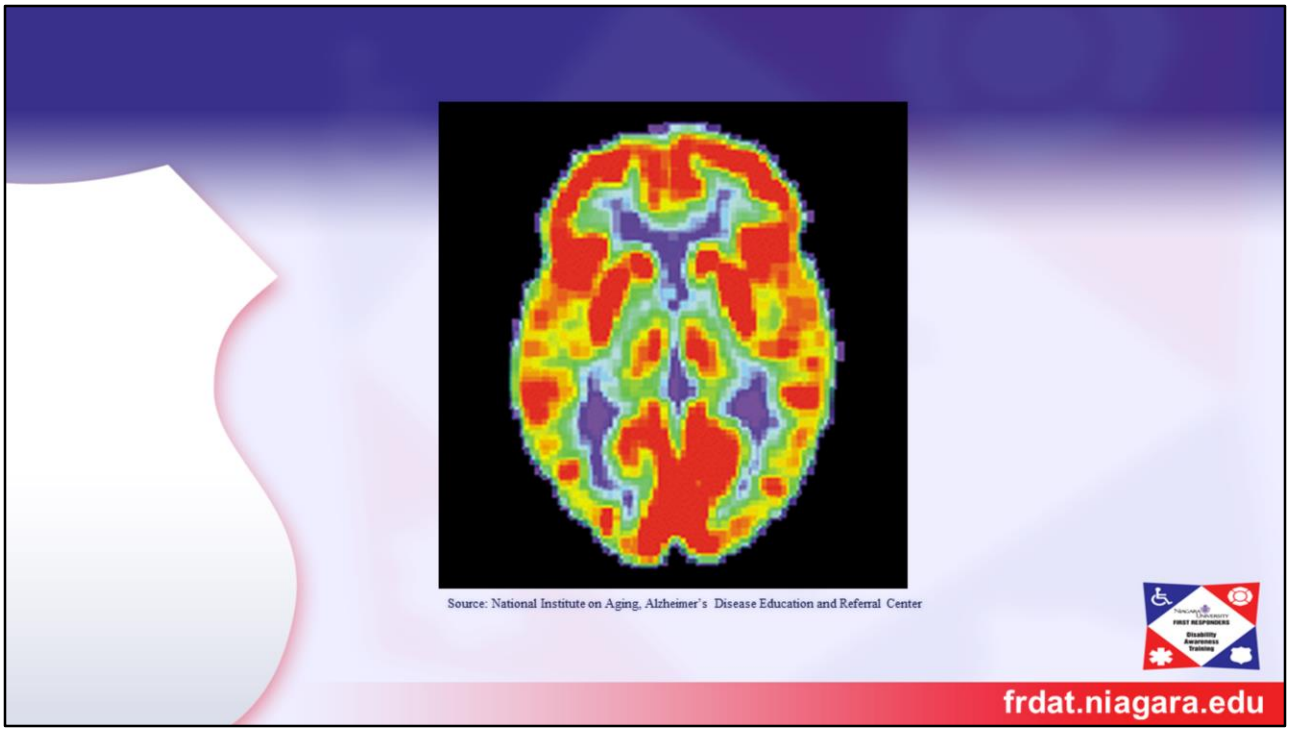
CLICK AND READ 3 POINTS

- Symptoms result from damage to the brain's nerve cells.
- Scientists do not know what causes the brain cells to die, but current research points to:
  - Plaques: deposits of a protein fragment called beta-amyloid (BAY-tuh AM-uh-loyd) that build up in the spaces between nerve cells.
  - Tangles: twisted fibers of another protein called tau (rhymes with "wow") that build up inside cells.
- Some people live only four years while others live as long as 20 years (Alzheimer's Association). There is no cure and the only treatment that exists only helps to slow down the symptoms.

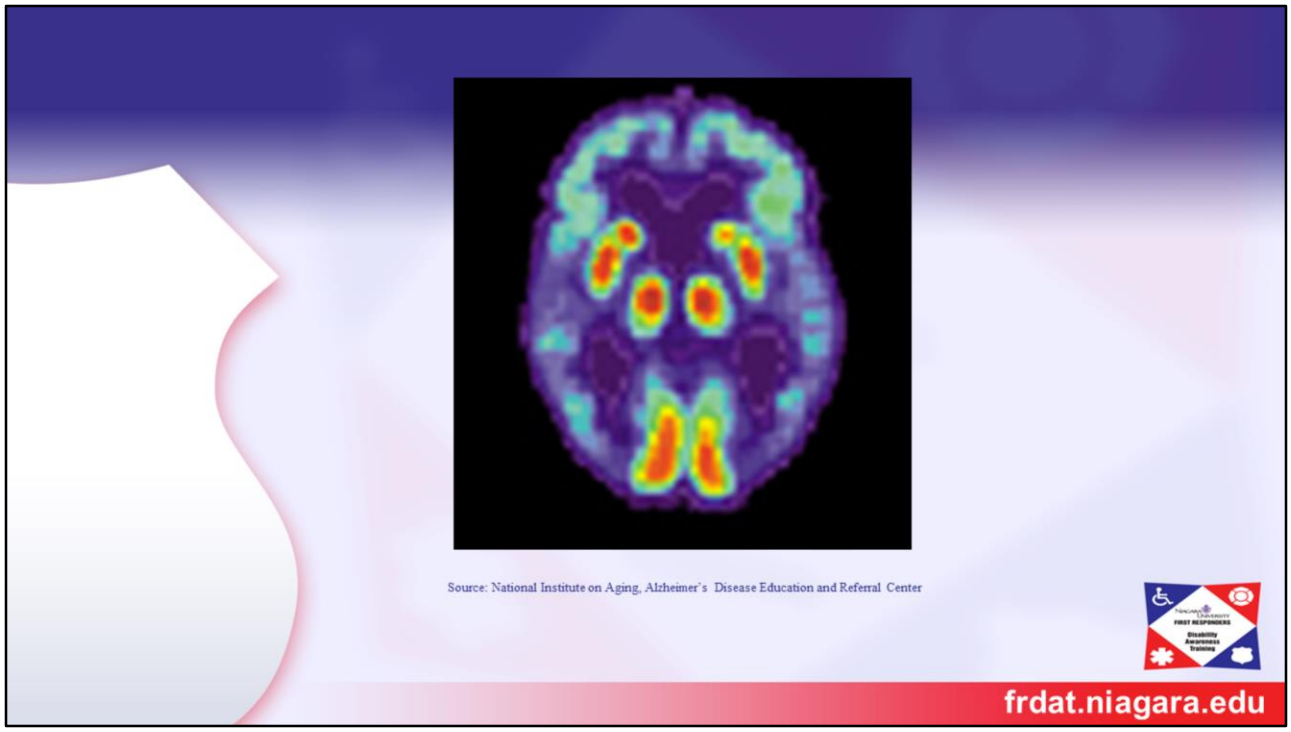


Let’s take a look inside the brain and see what happens when someone has Alzheimer’s disease.
Unraveling the Mystery of Alzheimer's Disease

(This is slow to start, but it runs)

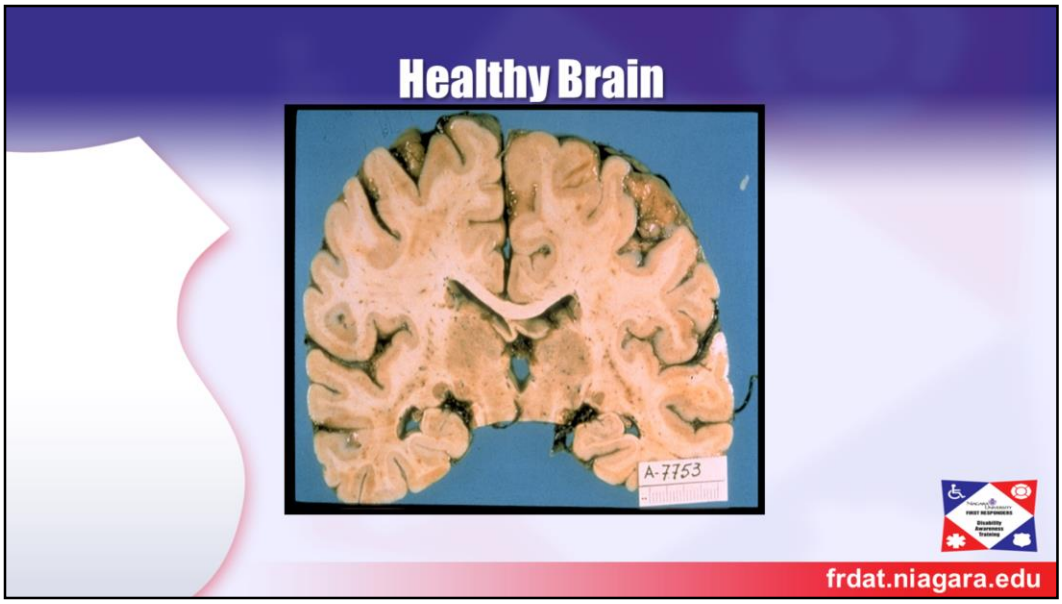


- Brain of individual without any disability.
- Red indicates activity in the brain, which is good.

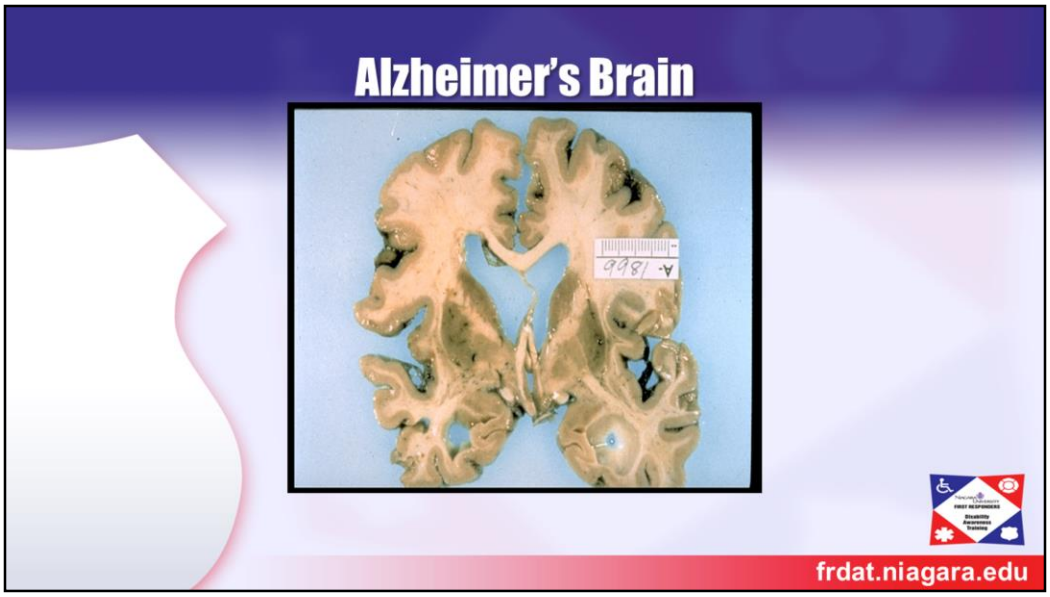


- Brain of individual with Alzheimer's disease.
- Note lack of red indicating brain activity is minimized.

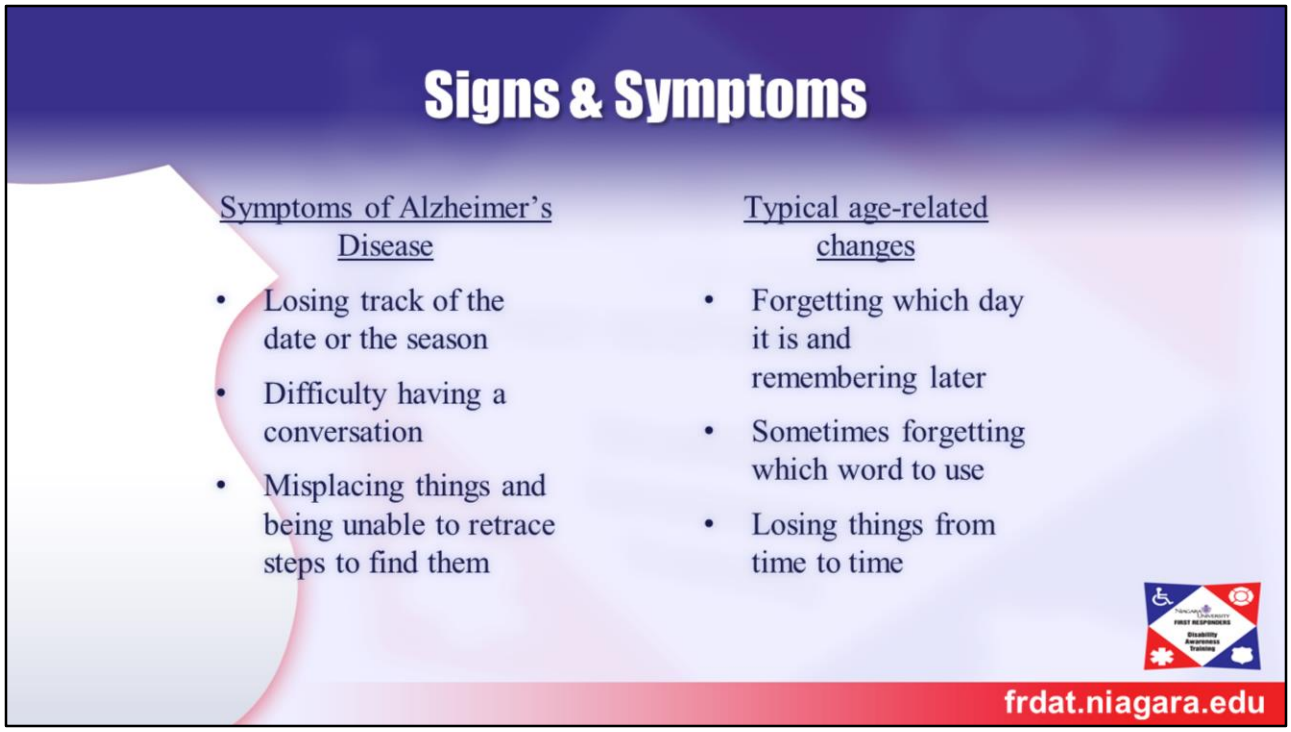
Go back one more time to previous slide to show difference.



- Notice the structure of the normal brain.



- Notice the shrinkage in this picture as well as loss of brain matter.

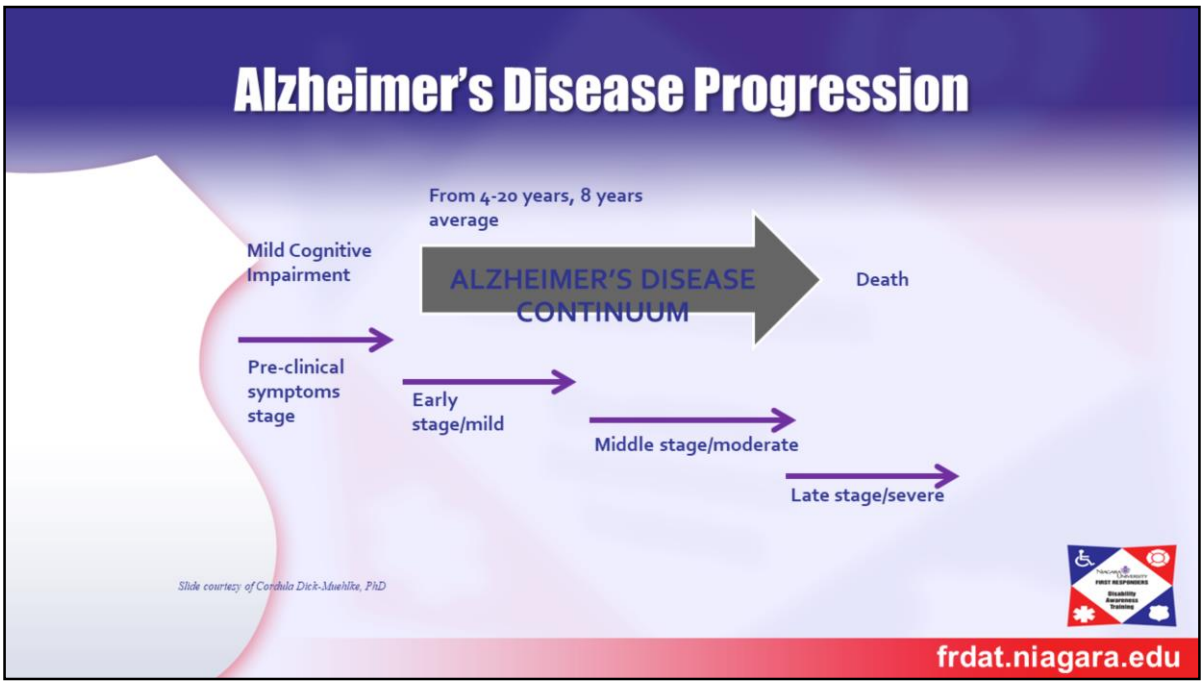


CLICK AND READ 6 BULLETS

The slide shows symptoms of AD compared to typical age-related changes, while the following are warning signs of the disease:

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing tasks at home, work, leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships (i.e. white curtains, black tiles or floors)
- New problems with words in speaking or writing
- Misplacing things, losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality
- Rapid mood swings due to anxiety, suspiciousness, or agitation
- Wandering or becoming lost and not knowing where one lives

- Officer Sutton notes the challenges memory loss will pose
- Accounts a woman he worked with who remembered the high school events 60 years prior but not able to recognize her children/caregivers



- Alzheimer's disease can last anywhere from 4-20 years, with an 8 year average. However, some people live much longer than this.

- We know that Alzheimer's disease begins with **a pre-clinical or pre-symptomatic stage**, which can begin decades before symptoms occur.

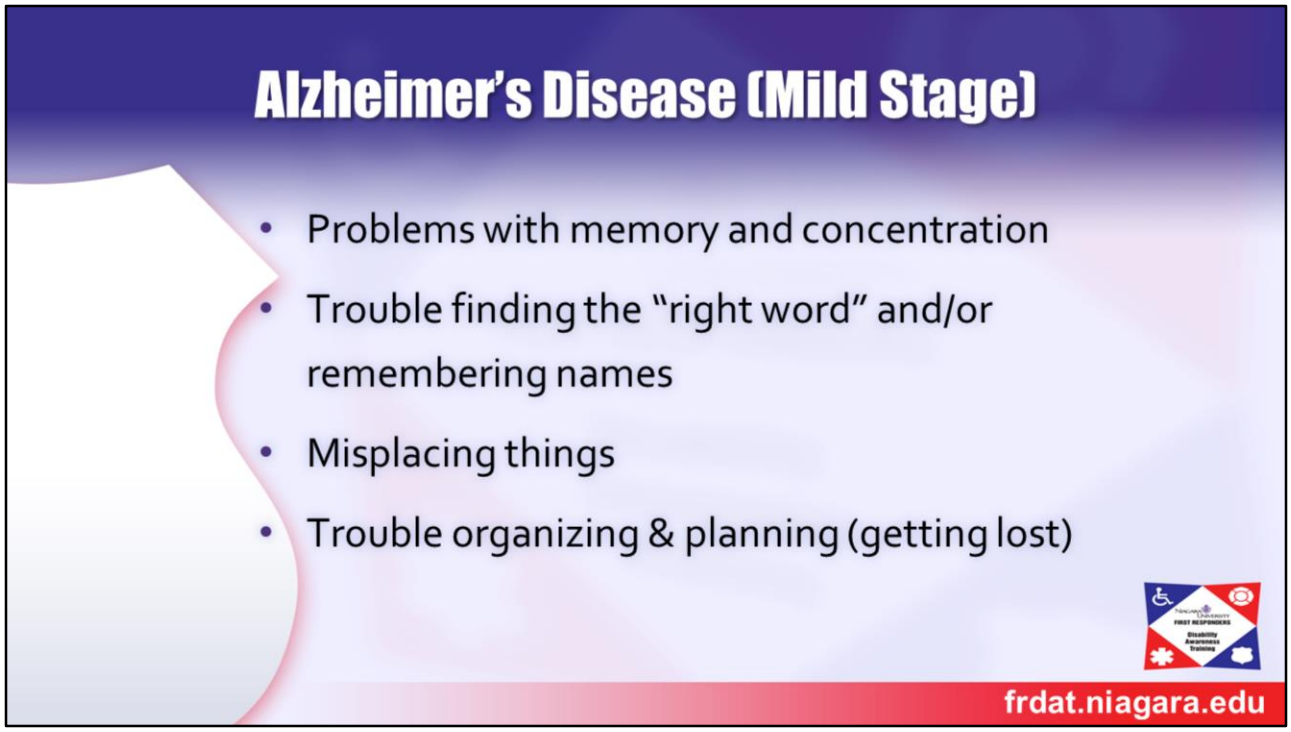
- **Mild cognitive impairment** may be the first symptomatic signs of this disease process, but mild cognitive impairment does not always progress into Alzheimer's disease.
- Mild cognitive impairment can be viewed as the "borderland" between normal aging and dementia. However, it is not severe enough to affect daily life.

- Alzheimer's disease progresses through **various stages---**

early, middle, and late. Some clinicians may speak about the 7 stages of Alzheimer's disease, but it can sometimes be challenging to categorize a patient into one of these specific 7 stages.

- Alzheimer's disease is **fatal**. Pneumonia and other co-existing conditions often cause death.

- Alzheimer's disease is **largely underreported on death certificates**, even though it is what truly caused the pneumonia or other co-morbidity. Though Alzheimer's disease has been reported to be the 6th leading cause of death in the United States, a recent study (2014, Bryan, et al. American Academy of Neurology) showed that Alzheimer's deaths are underreported and it may actually be the third leading cause of death, after heart disease and cancer.



CLICK AND READ FIRST BULLET

- In the early stages of Alzheimer's disease, a person has a **shift from their previous state**. Understanding a person's **baseline** helps determine if there has been a change.
- Caregiver or family member may be able to provide useful information to determine baseline.

CLICK AND READ SECOND BULLET

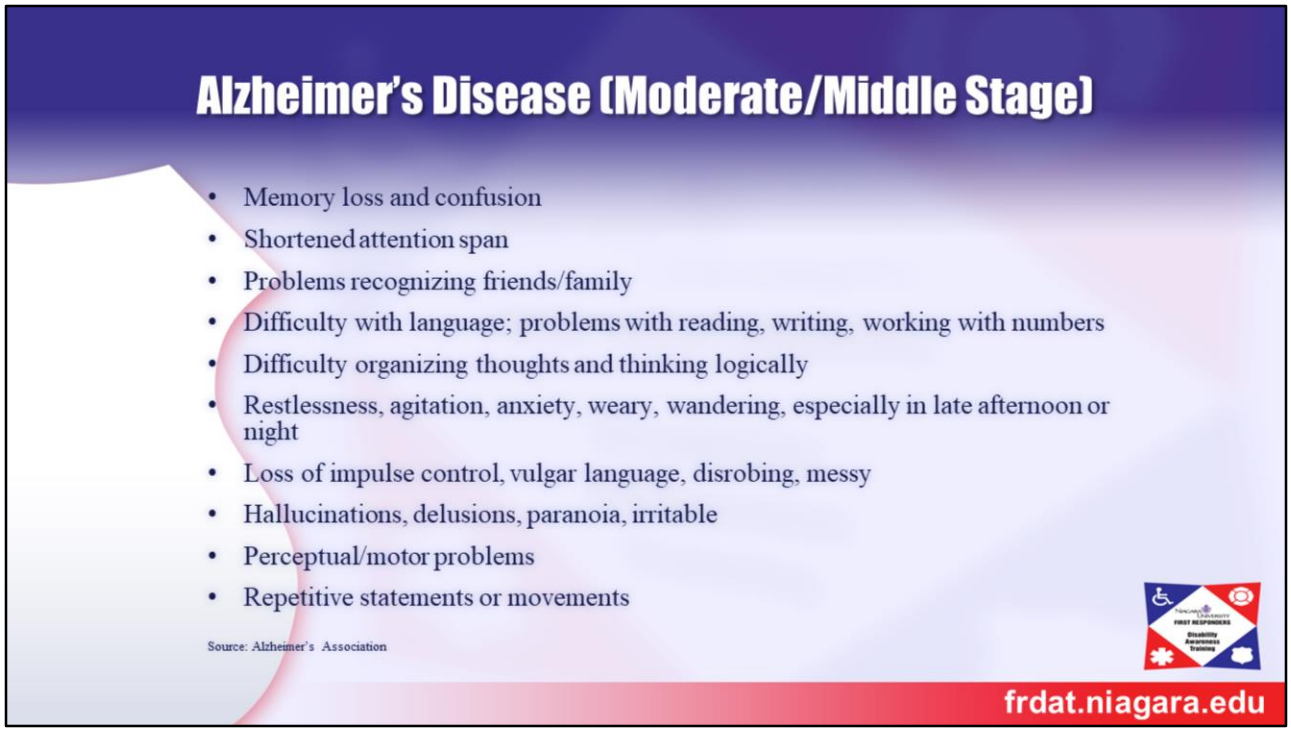
- **Recent memory loss is a hallmark feature** of early stage Alzheimer's disease; however, the **disease extends beyond memory loss**.
- A person may lack concentration, have a hard time finding the "right word," and/or remembering names

CLICK AND READ THIRD AND FOURTH BULLETS

- It is not uncommon to see that a person in the early stages misplaces things and also has trouble organizing and

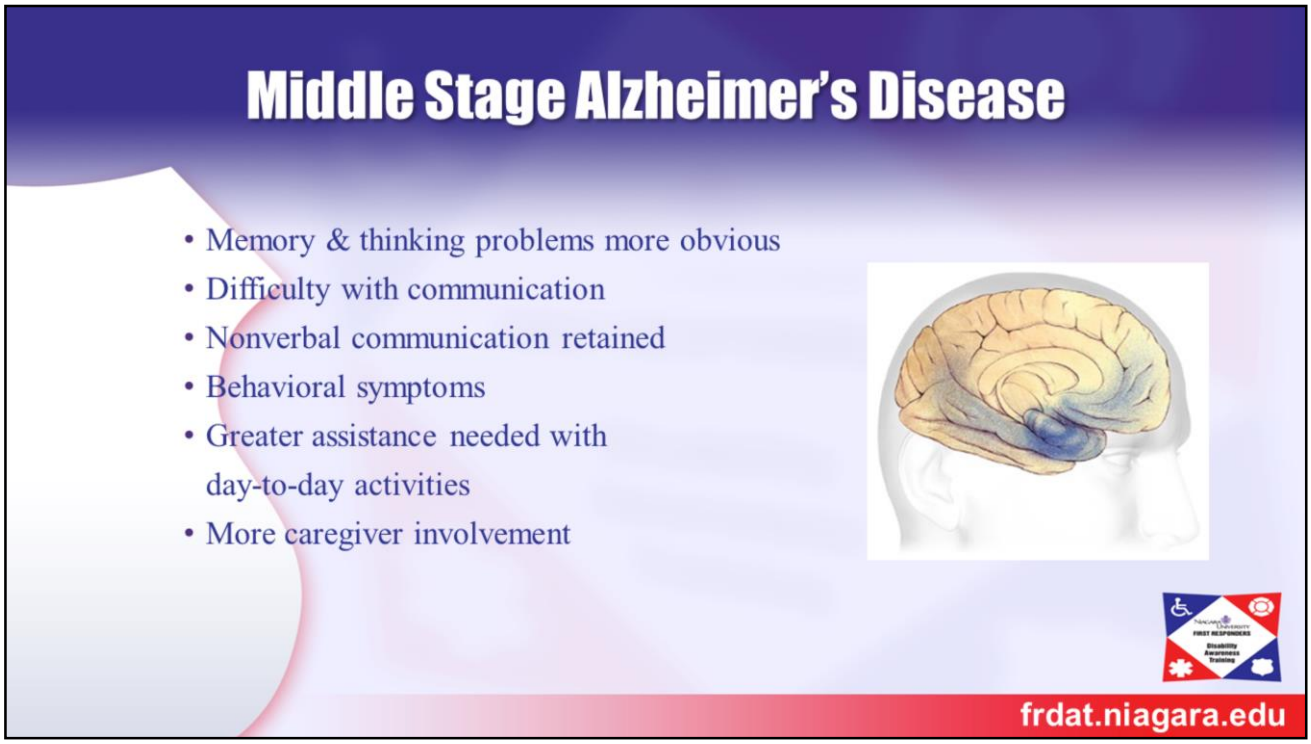
planning. This can cause them to be confused, disoriented, and get lost. Wandering is a significant issue and presents safety concerns.

About 6 in 10 people with Alzheimer's disease wander and this can have serious safety implications.



CLICK AND READ 10 BULLETS

- An individual in the moderate range of Alzheimer's disease may pose these challenges.
- Reflect back on previous page.



- In the middle stage of Alzheimer's disease, **memory and thinking problems** become more obvious.

- A person may have **difficulty with communication** in the middle stage of the disease. They may not be able to communicate with full sentences or they may not be able to understand what is being said to them. Though a person may lose verbal communication skills, he/she may retain nonverbal communication. Caregivers need to be aware of nonverbal communication and what it means.

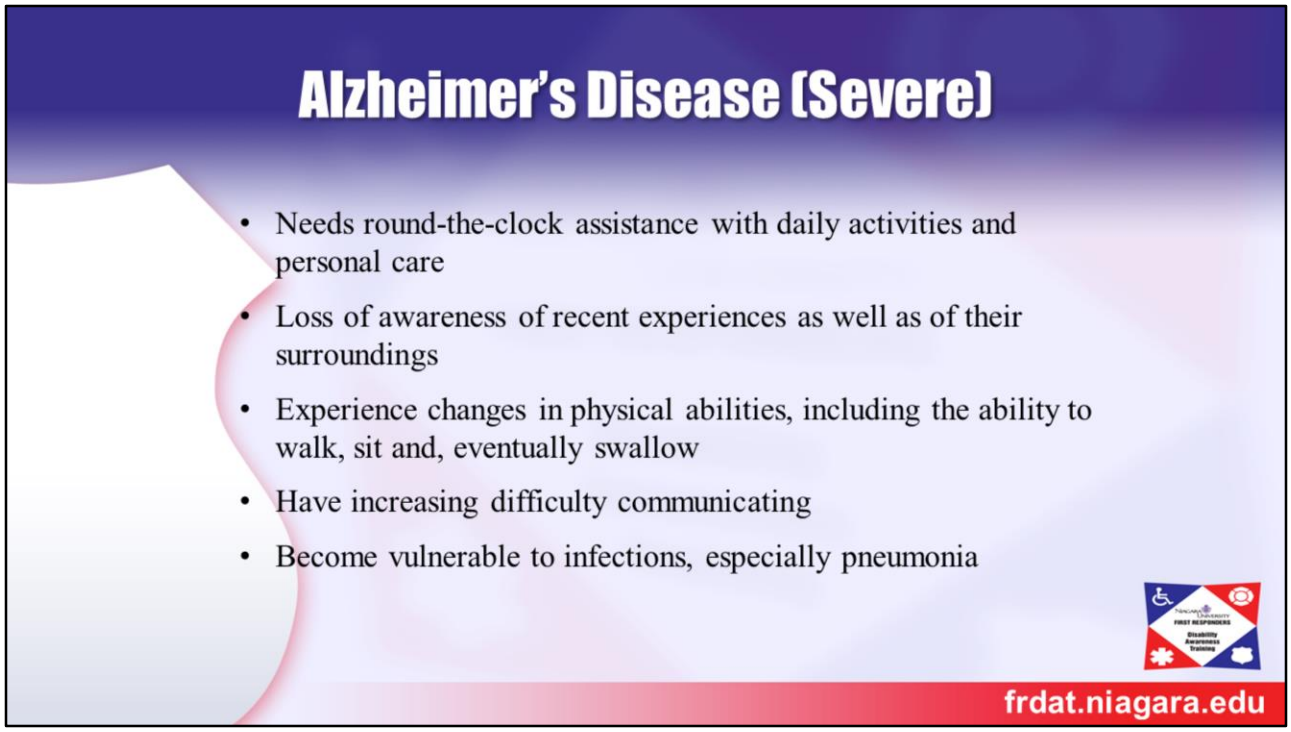
- **Behavioral symptoms** often manifest in the middle stage of the disease. These behavioral symptoms can be very challenging for caregivers. We will focus on behavioral symptoms later in the training.

- As Alzheimer’s progresses, people need more assistance with instrumental activities of daily living (everyday tasks such as managing money, shopping, using the telephone, taking medications, caring for pets, housework, preparing for meals and cleaning up) and **may also need assistance with activities of daily living** (such a bathing, toileting, feeding).

- Some people with Dementia will look healthy and appear to be fine to outsiders. They are able to **retain social skills** and appear "fine."

- During a brief interaction it can be easy for someone to "Pass" especially if you are only asking superficial questions or "yes" "no" questions.

- Caregivers and family members are likely to report that there is cognitive and functional decline; engaging **caregivers/family members may provide greater insight into the situation and to care needs**.



CLICK AND READ FIRST TWO BULLETS

- This care is necessary, yet exhausting for caregivers.
- Often it is this exhaustion that can lead to nursing home placement for the individual
- It can also lead to unintended abuse or "benign neglect," where the caretaker believes they are doing the best for the individual, while actually tasks or other care duties are neglected.
- That the individual cannot remember recent events or becomes confused and even frightened about where they are can add to these caretaker stresses

CLICK AND READ THIRD BULLET

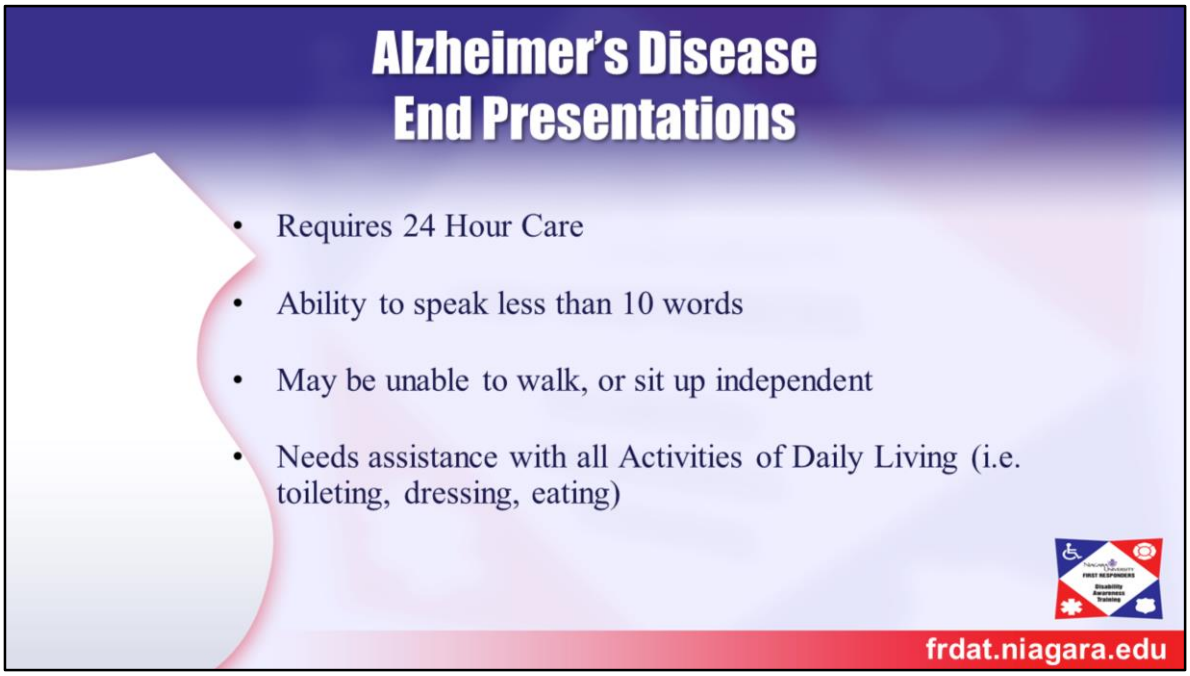
- When an individual becomes compromised, or loses the ability to swallow entirely, they are very likely to experience aspiration pneumonia (when liquids or solids are breathed into the lungs and decay, causing infection).

CLICK AND READ FOURTH BULLET

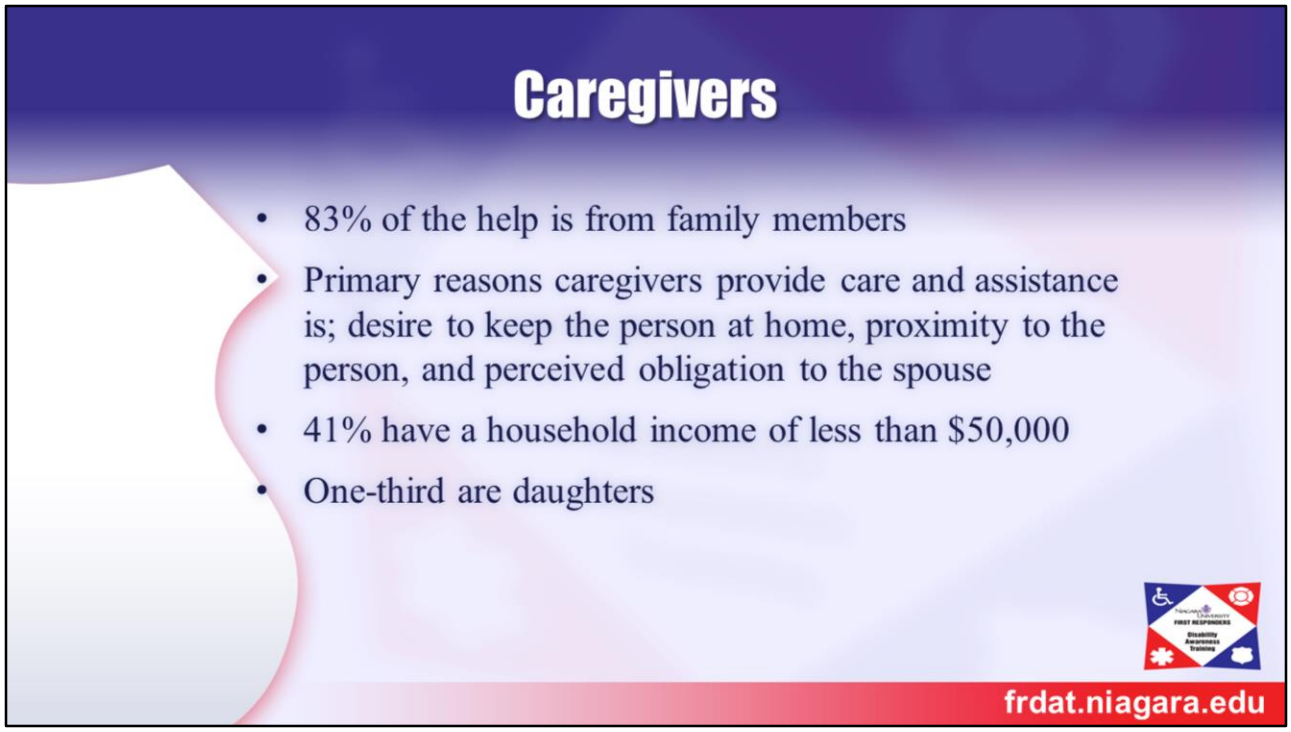
- The ability to speak may dwindle to less than ten words, or to an inability to speak or communicate beyond groans or sighs.

CLICK AND READ FIFTH BULLET

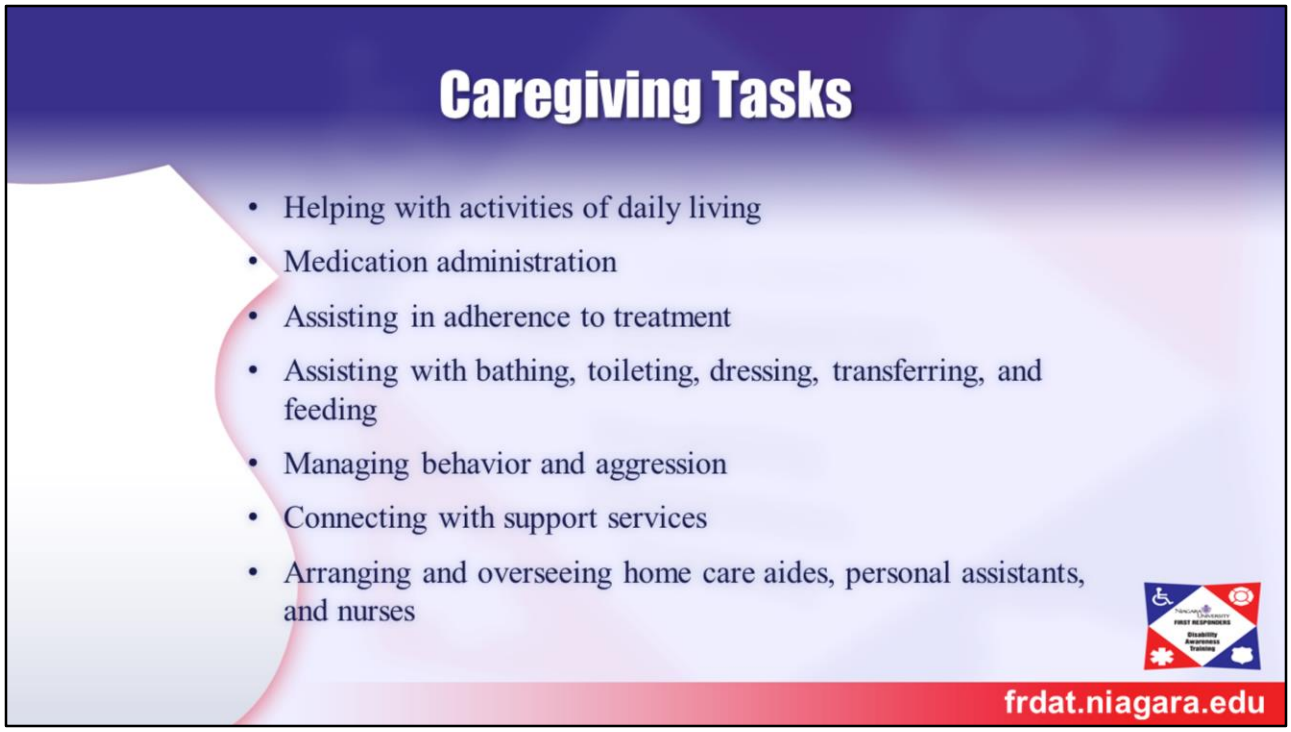
- People in the end stage of AD die, not from AD directly, but pneumonia, opportunistic infections, or malnutrition.



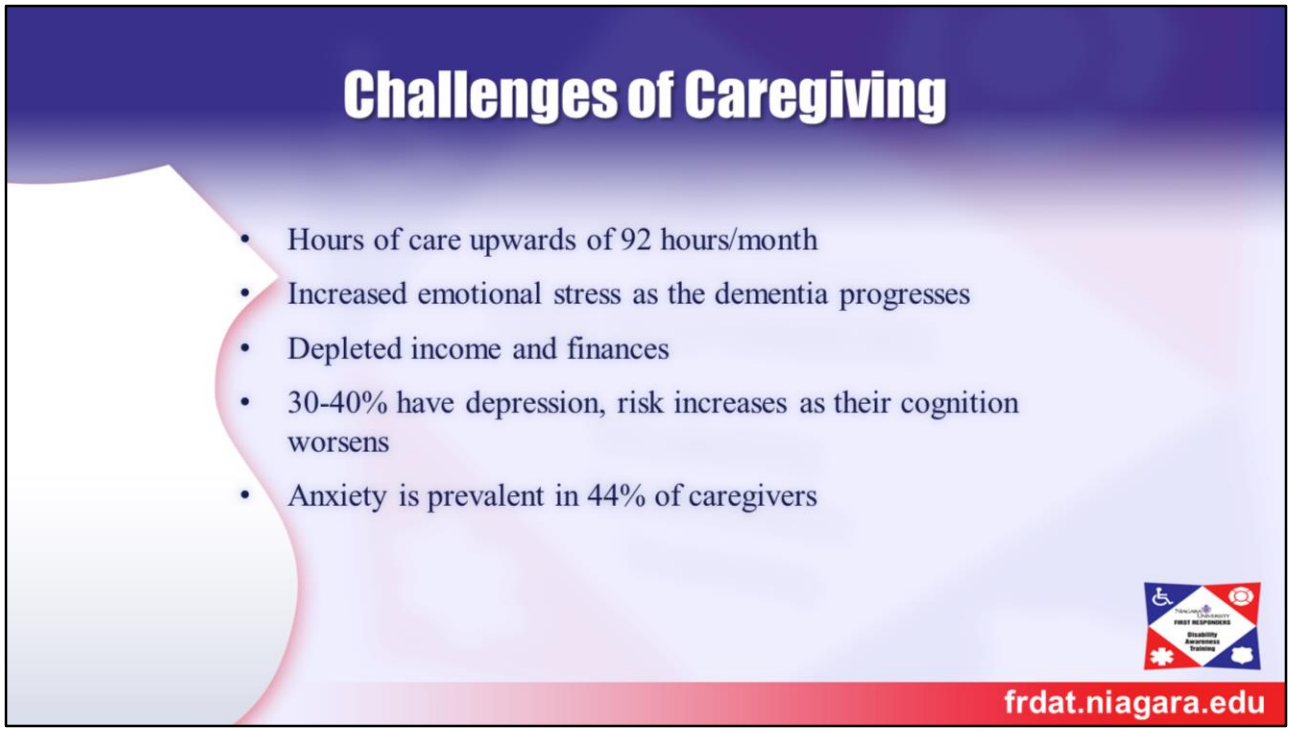
- For the most part, these individuals will rarely be in public. If they are, they will be accompanied.
- While an autopsy report will list Alzheimer's Disease based on the death certificate, the actual cause of death in about half the cases is respiratory system diseases with 25% related to circulatory system diseases
- It is the only top ten clause of death that cannot be prevented , cured, or even slowed



- Recall the numbers and dollars from the informational video as it related to caregivers



- Instrumental activities of daily living (IADLs) include household chores, shopping, preparing meals, transporting, MD appointments, and managing finances and legal affairs
- Behavior includes wandering, depressive moods, agitation, anxiety, and sleep disturbances
- Caregivers also help people get through a day, deal with family issues (related to their dementia), other health matters, and support and a sense of security.



- Over half of caregivers provide 21 hours/week. This can be exhausting
- As the person's dementia progresses, they pose more challenges to the caregiver. We will note challenges in the next section. Note how they would affect a caregiver.
- Depression can accompany the emotional stress. Caregiving will generally last a few years.
- 59% of family caregivers rated emotional stress as high to very high
- You may encounter a caregiver who is frustrated, exhausted, or tense. An understanding demeanor from an officer can be very comforting

ALZ Dementia-Challenges and Response

Objectives:

- Understanding Hallucinations, Paranoia and Delusions
- Locative Devices
- Aggression and Dementia
- Understanding Challenging Behaviors
- Communication and Alzheimer's
- Tips for Officers

Main points: Understanding that Alzheimer's dementia can present differently at any time is something Law Enforcement needs to be aware of. Appropriate response is needed in order to avoid any chance of escalating challenging behaviors in an individual. People with dementia may be confused and not be aware of time, place, or surroundings, even though it was once routine.

Content:

- PowerPoint: 30 pages
- Videos:
    - Wandering Video
    - Sleep-Wake Cycle
    - HBO: The Alzheimer's Project
    - IACP Alzheimer's Association Driver Assessment (Traffic Stop)
    - IACP Alzheimer's Association Grandma Goes Missing (On Foot)

- Handouts:
    - Preparing and Preventing Wandering
    - Keeping Home Safe
    - IACP's Alzheimer's Initiatives-Locative Technologies 101
    - Alzheimer's Aware-Adult Id Kit
    - Alzheimer's Aware-Informing the community on your department's website
    - Missing Persons with Alzheimer's Disease- Model Policy
    - Alzheimer's Aware Guide
    - Anger, Frustration & Fighting
    - Dementia and Driving
    - Getting Lost
    - Hallucinations

Resources:

- Alzheimer's Association: Phone: 1-800-272-3900: Website: www.alz.org:

Preparing for and Preventing Wandering

Alzheimer's disease causes millions of Americans to lose their ability to recognize familiar places and faces, increasing their risk of wandering and getting lost.

Six in 10 people with Alzheimer's disease will wander. Many people cannot remember their name or address. They may become disoriented and lost, even in their own neighborhood. Although common, wandering can be dangerous – even life-threatening. The Alzheimer's Association is working to help save lives through two innovative services:

- MedicAlert® + Alzheimer's Association Safe Return®, a 24-hour nationwide emergency response service for individuals with Alzheimer's or related dementia that wander or who have a medical emergency.
- Alzheimer's Association Comfort Zone®, a Web-based GPS location management service that can help families stay active.

Wandering: Who's at risk?

Anyonewith Alzheimer's or a related dementia who:

- Returns from a regular walk or drive later than usual
- Tries to fulfill former obligations that are no longer a part of daily life, such as going to work
- Tries to "go home" even when at home
- Is restless, paces or makes repetitive movements
- Has difficulty locating familiar places like the bathroom, bedroom or dining room
- Checks the whereabouts of familiar people
- Acts as if doing a hobby or chore, but nothing gets done (e.g. moves around pots and dirt without planting anything)
- Feels lost in a new or changed environment

Tips to Help Caregivers Prepare for and Prevent Wandering Behavior

Consider the behavior

- Be aware of who is at risk for wandering.
- Identify the most likely times of day that wandering may occur, and plan activities at those times.
- Provide opportunities for activities and exercise, such as helping with chores, listening to music and dancing.

- When night wandering is a problem, make sure the person has reduced fluids two hours before bedtime and has gone to the bathroom just before bed. Limit daytime naps, if possible.
- Monitor reaction to medications. Consult a physician, if necessary
- When the individual says that he or she want to leave to go home or to work, acknowledge the feelings and redirect the behabior.
- If wandering is in progress, redirect the individual's focus toward something that will bring him or her home again.

Consider the home environment

- Night-lights: Place throughout the home or facility.
- Locks★: Place out of the line of sight. Install slide bolts at the top or bottom of doors. **Note**: Never lock a person with dementia into an enclosed space alone (room, house, etc.).
- Door knobs★: Cover knobs with cloth the same color as the door. Use childproof knobs.
- Doors★: Camouflage doors by painting them the same color as the walls. Cover them with removable curtains or screens.
- Use black tape or paint to create a large black threshold resembling a hole in front of the door to reduce the likelihood that the person will approach and attempt to cross it.
- Warning bells: Place above doors.
- Monitoring devices: Try devices that signal you when a door is opened. Place a pressure-sensitive mat at the door or person's bedside to alert you to movement.
- Hedges or fence★: Put around the patio, yard or other outside common areas.
- Safety gates or bright colored netting★: Use to bar access to stairs or the outdoors.
- Furniture★: Consider providing a recliner or geriatric chair for the individual to sit and rest. It is comfortable and yet somewhat restrictive to the body. Use round-cornered furniture, placed against the wall. Remove obstacles.
- Noise levels and confusion: Reduce excessive stimulation caused by movement or noise.
- Common areas: Develop indoor and outdoor areas that can be safely explored.
- Clothing: Provide the person with brightly colored clothing to allow him or her to be seen easily by others.
- Labeling★: Label all doors. Use signs or symbols to explain the purpose of each room.
- Secure trigger items: Some people will not go out without a coat, hat, pocketbook, keys, wallet, etc. Making these items unavailable can prevent wandering.
- Avoid leaving a person with dementia alone in a car. He or she may attempt to leave.

Planning ahead

- Enroll in MedicAlert + Safe Return and/or Comfort Zone.
- Keep a list of people for the person with dementia to call when feeling overwhelmed. Have their telephone numbers in one location.
- Ask neighbors, friends and family to call if they see the person walking outdoors alone or dressed inappropriately.
- Keep a recent, close-up photo on hand to give to police.

- Make sure that MedicAlert + Safe Return has an updated photo and medical information.
- Know your neighborhood. Pinpoint dangerous areas near the home, such as bodies of water, open stairwells, dense foliage, tunnels, bus stops and roads with heavy traffic.
- Is the individual right or left-handed? Wandering generally follows the direction of the dominant hand.
- Keep a list of places where the person may wander to, like past jobs, former homes or a church or restaurant.

For safety and peace of mind, enroll in MedicAlert + Safe Return today:
Call **1.888.572.8566** or enroll online at **www.alz.org/safereturn**.

To learn more about **Comfort Zone** and whether it's right for you, call 1.877.259.4850 or visit www.alz.org/comfortzone.

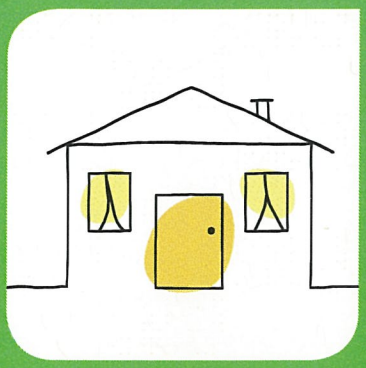
The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Updated November 2011

*These are meant to be suggestions only. Follow local, state and federal laws and codes.

Keeping Home Safe

People with Alzheimer's or dementia may have trouble knowing what is dangerous or making safe decisions. By helping him or her feel more relaxed and less confused at home, you can help stop accidents.



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- trip because of changes in balance or trouble walking
- have problems seeing clearly due to poor eyesight
- forget to turn off water, burners, ovens
- forget how to use knives, *etc.* or where to safely place burning objects

WHAT CAN YOU DO?

Keep Things Simple

- make sure rooms are neat
- place "often used" items in the same place
- remove things that might break and aren't needed

Look at the Floor

- remove small rugs, rugs that are thick, or rugs that might slide on floors
- don't shine or wax floors
- keep items off floors... cords, books, toys, bags, boxes, etc.
- make sure bathroom and kitchen floors are kept dry and avoid walking with wet feet
- use tables and chairs that are stable enough to lean on

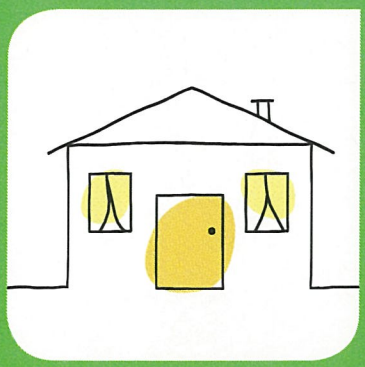
Remove Dangerous Items

- keep all medicines... vitamins, aspirin, prescriptions... in a locked box, cabinet, or drawer
- place knives, scissors, guns, sharp tools, matches, and lighters out of sight or in a locked area
- move all cleaning supplies to a high shelf or lock them away
- take off knobs from the stove and oven

Don't Leave Him or Her Alone

- in the kitchen with the stove or oven on
- in the bathroom with water running
- anywhere with burning cigarettes, cigars, or pipes
- near an open or unlocked door or gate

Seguridad en el Hogar



¿POR QUÉ PASA ESTE PROBLEMA?

- por cambios de balance y el equilibrio
- cambios de la vista
- no poder tomar buenas decisiones
- olvidan cómo usar objetos peligrosos (armas, cuchillos, etc.) de forma segura

Las personas con Alzheimer a veces no pueden entender lo que ven. Por ejemplo, los escalones pueden verse planos o las alfombras negras pueden parecer hoyos. También pueden tener problemas para entender situaciones peligrosas o tomar decisiones seguras. Para evitar estas situaciones, le ayudaría si usted hace algunos cambios al hogar.

¿QUÉ PUEDE HACER?

Evite el desorden

- mantenga los cuartos cómodos
- mantenga los artículos de uso diario en el mismo lugar
- guarde las cosas frágiles que estén al alcance, tales como: vidrios, espejos y vajillas

Revise el piso

- quite alfombras pequeñas que puedan causar tropiezos
- no deje cables electrónicos, libros, juguetes o basura en el piso
- asegúrese que el piso del baño y la cocina no estén resbalosos
- asegúrese que las sillas y mesas sean lo suficientemente estables como para apoyarse en ellas

Guarde objetos que puedan ser peligrosos

- mantenga TODOS los medicamentos (incluyendo vitaminas) bajo llave o fuera del alcance
- mantenga herramientas filosas fuera de vista o bajo llave, tales como: cerillos, cuchillos y pistolas
- guarde bajo llave todos los productos de limpieza, tales como: amonia, windex, jabón y detergentes
- quite los apagadores de la estufa y horno, y desenchufe aparatos electrónicos

No deje a la persona con Alzheimer sola

- con cigarrillos o un puro prendido
- en la cocina con el horno o estufa encendida
- con la puerta abierta o sin seguro
- en el baño con el agua corriendo

MedicAlert® + Alzheimer's Association Safe Return®

MedicAlert®
Emergency Response Line:
1-800-625-3780
www.alz.org

Overview:

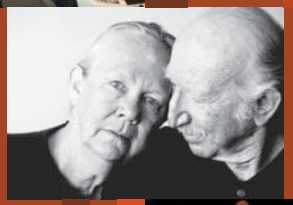
MedicAlert® + Alzheimer's Association Safe Return® is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency.

If an individual with Alzheimer's disease or a related dementia wanders and becomes lost, caregivers can call the emergency response line to report it. A community support network will be activated, including local Alzheimer's Association chapters and law enforcement agencies, to help reunite the family member or caregiver with the person who wandered.

If a citizen or emergency personnel finds the member, they can call the toll-free number listed on the member's ID jewelry. MedicAlert + Safe Return will notify the member's listed contacts, making sure the person is returned home.

INTERNATIONAL ASSOCIATION OF CHIEFS OF POLICE
515 North Washington Street Alexandria, VA 22314
(800) THE-IACP alzheimers@theiacp.org

This project was supported by Grant No. 2010-SJ-BX-K005 awarded by the Bureau of Justice Assistance. The Bureau of Justice Assistance is a component of the Office of Justice Programs, which also includes the Bureau of Justice Statistics, the National Institute of Justice, the Office of Juvenile Justice and Delinquency Prevention, the Office for Victims of Crime, the Community Capacity Development Office, and the Office of Sex Offender Sentencing, Monitoring, Apprehending, Registering, and Tracking. Points of view or opinions in this document are those of the author and do not necessarily represent the official position or policies of the U.S. Department of Justice.



IACP's Alzheimer's INITIATIVES

Safeguarding the Maturing Population

First Responders Guide to Identify Locative Technologies

Locative Technologies 101

www.theiacp.org/alzheimers

Use this reference guide to be aware of what types of technologies are on the market, how they work, what they look like, and who the point of contact is for that particular device.

Listed are the various types of tracking systems used specifically for persons with Alzheimer's disease and dementia.

60% of the 5.4 million Americans who currently have Alzheimer's disease will wander at some point in their disease.

Be Aware

- **No system is 100% accurate.** Technological devices have limitations.
- Make sure the system is updated and in working order before beginning any program.
- Consult with a physician and law enforcement before beginning any program. They may have valuable guidance on a locative program to use.
- Weather, terrain, and time of day may be a factor in effectiveness.
- Most services require a monthly subscription or an initial investment in the product.
- Make sure that the program has trustworthy cyber-protection components.
- Some products need to be recharged regularly, which means that the at-risk-person is unprotected while the unit is charging.
- Understand that elder locative technologies are not the same as a 24-hour companion.

Satellite-Based Positioning Systems

Overview: Satellite-Based Positioning systems or Global Positioning systems (GPS) use a series of satellites that orbit the earth, broadcasting signals which are picked up by a network of receivers or in this case a recipient, such as an elderly person, who is wearing the device. In order for the GPS device to work, effectively, there needs to be a clear "line of sight" between the receptor and the satellites.

Cellular devices and satellite-based databases are also included within this category.

Advantages:

- Worldwide capabilities
- Accurate reading at any time of the day
- Real time tracking
- Location information available in a matter of seconds
- Data security and cell phone alert features

Disadvantages:

- May not be able to track inside buildings
- All satellites need to be operational
- Monthly monitoring fees
- Generalized, not specific location tracking
- Obstruction will produce inaccurate readings
- GPS maps need to be kept updated

Garmin
cartography@garmin.com
(Attn: Law Enforcement Inquiries)
www.garmin.com/us

LiveViewGPS, Inc.
1-888-544.0494
www.liveviewgps.com

Global Tracking Group
1-800-774-9808
www.globaltrackinggroup.com

Tracking System Direct
951-704-9503
www.tracking-system.com

Land-Based Tracking Systems

Overview: Land-Based tracking systems such as Radio Frequency Identification (RFID) based systems work through a transmission of radio waves between a transponder, antenna, and a receiver. The RFID chip transmits a signal to the receiver through the antenna and provides data on a person's location.

RFID systems are geared toward professional caregivers (i.e. hospitals, law enforcement).

Advantages:

- Signals go through most walls
- Precise location recognition
- Some systems provide professional training
- Custom room/vicinity monitoring*
- Ability to be intergraded with electromagnetic locks, access control systems, and other security devices*

Disadvantages:

- Signal can be obstructed by physical barriers
- Strength of signals may vary according to distance
- Cost of implementing a program can be expensive
- Size of transmission and reception antennas are a factor in receiving signals

*Not all RFID systems have this capability.

Project Lifesaver
877-580-LIFE (5433)
projectlifesaver.org

LoJack: SafetyNet
1-877-434-6384
www.safetynetbylojack.com

RF Technologies: Code Alert
1-800-669-9946
www.rft.com/codealert/wandering-management.aspx

Care Trak
1-800-842-4537
www.caretrak.com

Network Assisted GPS (A-GPS)

Overview: Network Assisted GPS (A-GPS) or Hybrid Tracking systems combine elements from two or more systems in-order to increase accuracy and responsiveness. A-GPS technology works in conjunction with GPS systems by using cell towers to triangulate locations.

Advantages:

- Combines elements from two or more systems (i.e. GPS, cellular towers, database systems)
- Provides accurate readings, particularly in enclosed areas
- Customer controlled geo-fencing
- Information receiving is immediate and can be stored into a database system
- Instant cell phone notifications
- Less processing power is required by the device which saves battery life

Disadvantages:

- Dependent on reliable cell phone service
- Phone must be equipped with a GPS chipset
- If there is a disturbance in one technology then the effectiveness of the others may be at risk
- Not easily manageable to those who are unfamiliar with recent/trending technology
- Cost of service and devices can be expensive

Adiant Solutions
480-970-2574
www.adiant-solutions.com

Lok8u
1-888-423-1887
www.lok8u.com

Comfort Zone
1-877-259-4850
www.alz.org/comfortzone

Laipac Technology, Inc.
1-877-S911GPS
www.laipac.com

Please place a current photo here

or have one available for use by law enforcement

Questions to expect from your local law enforcement agency about a missing adult:

When and where were they last seen?

Have they wandered previously?

Did they leave on foot or in a vehicle?

If missing before, where did they go and where were they found?

Are they carrying a cell phone? Identification?

Would they recognize police or someone in uniform?

Do they have weapons or access to weapons?

Would they have a negative reaction to being approached by someone in uniform?

Do they have money/credit cards with them?

Do they know how to use public transportation?

Do they remember their name? Address?

Family Resources

Consider Participating in a Registry!

The Alzheimer's Association offers several programs which support families with a loved one with Alzheimer's disease.

MedicAlert® FOUNDATION

Live 24 hour emergency response for wandering and medical emergencies

+

safe return®

alzheimer's association®

Learn more about these and other programs at

www.alz.org (800) 272-3900

INTERNATIONAL PROJECT LIFESAVER "BRINGING LOVED ONES HOME"

For more information, please visit

www.projectlifesaver.org

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Adult Id Kit

Alzheimer's Aware

Recognize. React. Respond.

Preventing a tragedy is sometimes as easy as having the right information when a situation occurs.

If you have a loved one who has Alzheimer's or dementia, having up-to-date information and taking quick action can make a difference in finding someone who has wandered off.

Please take the time to fill out the enclosed information and update it annually with a recent picture.

If your loved one goes missing
CALL 9-1-1 !

place department logo here

Identifying Information For Person With Dementia

Personal Information

Name: _____

Nickname: _____

Address: _____

_____

Is this a care facility? ☐ Yes ☐ No

Date Of Birth: _____

Place Of Birth: _____

Sex: ☐ Male ☐ Female

Race: _____

Height: _____ Weight: _____

Eye Color: _____

Glasses? ☐ Yes ☐ No

Hearing Aid? ☐ Yes ☐ No

Walking Aid (cane, walker)? ☐ Yes ☐ No

Hair Color: _____

Hair Style: _____

Scars/Marks/Tattoos:

_____

_____

_____

Medical Information

Registered with Medicalert or local registry?
☐ Yes ☐ No

Wearing an electronic tracking device, bracelet or tag? ☐ Yes ☐ No

Medical Conditions
(physical or mental impairments):

_____

_____

Medications: _____

_____

_____

Allergies: _____

_____

Attending Physician:

_____

Phone Number: _____

Maintain the individual's banking and credit card information *in a secure place* to be available to law enforcement should they go missing.

Contact Person: _____

Phone: _____

Vehicle Information

Make: _____

Model: _____

Color: _____

Style (4-Door, 2-Door, SUV, etc.) _____

License Plate #: _____

State: _____

Does the individual have a cell phone?
If Yes, number: _____

Other Helpful Information

Current/Former Occupation:

_____

Locations the person may visit or past residences:

_____

_____

_____

Other identifying features or important information that might assist police:

_____

_____

_____

Alzheimer's Aware

Informing the community on your department's website

Your department's website is an essential tool for informing the community about Alzheimer's Disease. Utilize the language below to make sure your website is a one-stop shop for information and involvement opportunities.

Alzheimer's Disease Impacts All of Us

With more than 5 million sufferers and the numbers growing – all of us are affected by the disease whether we know it or not. Either you know someone who has Alzheimer's, you care for someone who has the disease or know someone who does, you live near someone who is a sufferer, you are a business owner or work in a business where someone with Alzheimer's may shop, eat, or visit, you drive a sufferer or caregiver on your bus, taxi, or train, or you are driving next to someone who either has the disease, or is concerned about a loved one that does. While we can't prevent the disease yet, or cure it, all of us can be in a position to help.

What does Alzheimer's have to do with Law Enforcement?

Because of the effects of the disease, persons who suffer from Alzheimer's may end up coming into contact with law enforcement because of issues such as:

- erratic driving,
- wandering away from home or their caregivers and being reported as a missing person,
- trespassing on property where they lived years ago but, don't remember that they moved from, or a host of other potential situations

Get educated about Alzheimer's Disease and its effects

If you are a caregiver, learn what you can do to prevent wandering, be prepared in the event that a loved one does wander away, or enroll your loved one on a registry or locative device program.

Realize. Recognize. React.

If you witness a situation where a neighbor or individual you come across appears to be alone, lost, confused, or exhibits signs of dementia – call the local police department and report what you have witnessed. In many cases, persons with Alzheimer's who wander will come in contact with people along their way. This interaction may be the key to finding this person and keeping them safe!

CPSJ
Center for Public Safety and Justice

BJA
Bureau of Justice Assistance
U.S. Department of Justice

LOCATIVE TECHNOLOGIES

There are many types of Locative Devices available on the market. Our Department does not endorse one product over another. What will work best for you depends on the specific situation your loved one lives in, including locale. Three programs we are aware of include:

Safe Return Program + Medic Alert	http://www.alz.org/care/dementia-medic-alert-safe-return.asp
Comfort Zone	http://www.alz.org/care/alzheimers-dementia-gps-comfortzone.asp
Project Lifesaver	http://www.projectlifesaver.org/

KEY FACTS ABOUT ALZHEIMER'S

- Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys memory and thinking skills and, eventually the ability to carry out simple tasks of daily living.
- More than 5 million people in the U.S. currently suffer from Alzheimer's Disease.
- A government-funded report confirms that the number of people in the USA with Alzheimer's disease will almost triple by 2050 to 13.8 million from the current 5 million.
- An estimated 800,000 individuals with Alzheimer's (more than one in seven) live alone.
- Of those who live alone, up to half of them do not have an identifiable caregiver.
- Alzheimer's is the only disease among the top six killers in the USA for which there is no prevention, cure or treatment.
- Caring for a person with Alzheimer's disease is physically, emotionally, & financially challenging. The demands of day-to-day care, changing family roles, and difficult decisions about placement in a care facility can be hard to handle.
- According to a national poll more than 1 in 7 American workers are active or former caregivers for someone with Alzheimer's or another dementia.
- It is estimated that between 60-70% of persons with Alzheimer's will wander one or more times during their disease's progression.

If you come in contact with a person that may be suffering from Alzheimer's or dementia that appears lost or confused, please contact:
XXX-XXX-XXX

In an emergency situation, dial 9-1-1

For more information on the disease or community resources available to deal with Alzheimer's:

US Department of Health and Human Services,
Administration on Aging
http://www.aoa.gov/

National Area Agencies on Aging Association
http://www.n4a.org/

The National Institute on Aging
www.nia.nih.gov/Alzheimers

The local Area Agency on Aging
www.

State Department on Aging / Department of Elder Affairs
www.

The Alzheimer's Association
24/7 Help Line: 1-800-272-3900
www.alz.org

The Alzheimer's Foundation
http://www.alzfdn.org/

Alzheimer's Aware

MISSING PERSONS WITH ALZHEIMER'S DISEASE

Model Policy

Effective Date	*Number*
September 2010	

Subject
Missing Persons with Alzheimer's Disease

Reference	*Special Instructions*

Distribution	*Reevaluation Date*	*No. Pages*
		5

I. PURPOSE

The purpose of this policy is to provide guidance for the response and investigation of missing persons with Alzheimer's disease and related dementias (AD/D).

II. POLICY

The mind-set of a person with AD/D is much different than that of other missing persons. Therefore, questioning, report-taking, investigation and search considerations should be appropriately expanded.

It is the policy of this agency that 1) during agency employee contacts and encounters with older adults, consideration will be given to the potential that the individual is lost but is not yet reported missing, or is spatially disoriented and at high risk of becoming lost; 2) persons found with AD/D, whether by an agency employee or a Good Samaritan, are provided with assistance that is appropriate for the AD/D medical considerations; and 3) reports of missing persons with AD/D will be treated as an emergency and a search will begin as soon as reasonably possible.

III. OVERVIEW OF THE DISEASE

AD/D is hallmarked by memory loss and changes in a person's ability to think clearly; to recognize persons, landmarks, or other familiar objects; and often, causes him or her to act irrationally under what most persons would consider normal situations. While AD/D most commonly afflicts older adults, a small percentage of cases include early-onset AD/D beginning as early as age 35.

Law enforcement officers may come in contact with persons who manifest symptoms of AD/D in a variety of situations. Those missing with AD/D fall into three categories: 1) individuals who seem normal and oriented during encounters with law enforcement and other persons, and who may not be classified as missing but whose behaviors suggest that they are lost, or at risk of become lost; 2) those who are missing but have not yet been noticed or reported missing by caregivers; and 3) those who have been reported as missing by caregivers.

IV. PROCEDURES

A. Identifying the At-Risk Older Adult

Law enforcement officers may encounter individuals who, while initially coherent, are subsequently recognized as being confused and disoriented. In these situations, officers should ask the individual basic evaluation questions, such as the following:

1. Where are you coming from? Where are you going to?
2. What route are you taking to get there? Who are you meeting?
3. What is your full name and address? What is your phone number?
4. What day of the week is it? What month is it?
5. Can you tell me what city and state we are in?
6. What time is it right now? (Answer should be correct within one hour.)

B. If the individual does not provide correct answers to these questions law enforcement personnel should secure the person at his or her current location and consult with their immediate supervisor on appropriate actions. If a substantial degree of confusion and disorientation is identified, the individual should be temporarily detained in a reasonably comfortable setting and attempts made by officers to locate the individual's family or care facility. If these efforts are not successful, the person should be taken to a local hospital or care facility as available.

C. Initial Report Taking
   1. There is no waiting period for reporting a missing person with AD/D.
   2. The initial report taker shall gather information in order to initiate a response appropriate for the situation. Such information includes the following:
      a. Name, age and physical description of the person; a recent photo, if available; and the relationship of the reporting party to the missing person.
      b. Time and place of last known location and description of the clothing the person was wearing when last seen. Ask if the clothing is weather appropriate.
      c. The extent of any search for the person currently being undertaken.
      d. Whether the person has been missing on prior occasions and where the person has gone in the past or where they were located previously.
      e. The current physical condition of the person and whether the person is taking prescription medication or has a co-existing medical condition. If the person takes medication, when was the last dose taken and how long can the person be without it without experiencing life-threatening or other serious consequences.
      f. Which door or exit did the person leave from?
      g. Did the person leave on foot or in a car?
   3. In addition, the following questions should be asked:
      a. Is the person carrying identification, medical alert devices, or similar items?
      b. Would the person recognize and respond to police officers or someone in uniform? Would the person be fearful of police or uniforms for any reason?
      c. Does the individual have weapons or access to weapons?
      d. Is the current location near the person's hometown – could the person have gone to a former residence, workplace, church, or other familiar location?
      e. What is the person's general daily routine?
      f. Can he or she still use money and does he or she have any with him or her? Is he or she capable of accessing cash?
      g. What neighbors does he or she know well?
      h. Are there activities he or she seeks out or enjoys? What would he or she find interesting as it relates to locations?
      i. Does he or she know how to use public transportation? Does he or she use it regularly?
      j. Does the person still remember his or her address or phone number?
      k. Is the person drawn to certain landmarks, buildings, or objects?
      l. Will the person go away from the sun or towards it?
      m. Does the person have fears of crowds, strangers, or certain environments?

D. Preliminary Investigation
   1. Responding or assisting officers should do the following:
      a. Conduct a full search, as soon as reasonably possible, of the home or care facility and surrounding premises and curtilage, including unusual locations such as false ceilings, A/C venting, toy-boxes, sink basins or cabinets, and so forth. A search of neighbors' yards should also be conducted.
      b. Initiate a broader search if a thorough search of the home and immediate area is unproductive.
      c. Upon verification of a missing person, complete a "missing – critical" or endangered missing persons report and initiate an alert if Silver Alert, Endangered Persons Alert, or similar alerts exist in the area or jurisdiction where the person has been reported missing. Make appropriate entries in state and national information databases in accordance with established procedures (e.g.: adjacent jurisdictions, state or commonwealth department of public safety, National Crime Information Center, fusion centers, and LEADS).
      d. Check for indications of missing personal belongings, particularly money and other valuables.
      e. Check for any suggestion of foul play or accident.

f. Secure the premises or area where the person was last seen as a crime scene.
g. Request that one person with whom the missing person is familiar remain at the place last seen in the event the person returns and to serve as a consistent point of contact.

2. In the case of persons designated as "missing - critical," a supervisory officer may do the following:
   a. Request or assign a specific dispatcher to handle calls relative to this case and direct the dispatcher to broadcast all relevant information necessary to identify the missing person to all persons on duty.
   b. Request that the shift commander authorize mobilization of resources necessary for an area search.
   c. Establish an Incident Command Center and implement the Incident Command System.
   d. Determine whether to use local media to help locate the missing person and use where deemed necessary with the approval of the law enforcement supervisor and the missing person's family.
   e. Determine the best use of developed communication networks: BOLOs, texting programs, social media, reverse-calling systems, fusion centers, and other outlets.
   f. Conduct outreach through other governmental/contracted employees with radios and vehicles such as parks/facilities, road crews, waste management, and related personnel.

E. Search and Operational Considerations and Guidelines

Law enforcement officers should understand that standard grid-style searches may not be useful with a missing AD/D person. Instead, officers should determine if the person left by car or on foot.

1. If by car, officers should:
   a. Ascertain or approximate the amount of fuel in the vehicle and construct a search radius using this information. If the fuel cannot be approximated, begin a routine search with a 5-mile radius using available officers and volunteers.
   b. Notify adjacent counties.
   c. Initiate credit card and/or bank inquiries to determine if and where purchases have been made since the person was last seen.
2. If on foot, officers should:
   a. Begin a thorough foot search with a 1.5-mile radius using available officers and volunteers.
   b. Consider the dominant-hand theory: the person will follow the path of their dominant hand, that is, if the person is right-handed, he or she will likely be making right turns, following right, etc.
   c. Call in other available assets, such as search helicopters, volunteer teams, social services, etc.
   d. Search areas of thick vegetation, near bodies of water, and near highways; areas that have cover (natural or man-made), and residential yards. Special attention should be paid to areas such as culverts, drainage areas, wooded transitional areas between housing developments, etc.
   e. Consider obscure hiding locations: junkyards, drainage trenches, building roofs, abandoned buildings and vehicles, commercial ventilation systems/ducts, etc.
   f. Canvass area businesses and other easily accessible buildings.
   g. Expand radius as time and weather dictate.
3. Search considerations:
   a. Searchers should be aware that missing persons with AD/D likely will not respond to their name being called. Missing persons may perceive that they are "in trouble" and further hide or seclude themselves.
   b. If the person is located, those having initial contact with the person should do the following:
      (1) Use low, calm voices and short, simple sentences or questions
      (2) Clearly identify themselves and explain what they are doing
      (3) Ask permission before touching
      (4) Use simple instructions and positive reinforcement
      (5) Allow plenty of time for the person to respond
      (6) Limit volume of radios and curtail the use of lights and sirens, if possible and practical, as this may further agitate the person
      (7) Avoid placing the person in handcuffs (in cases of arrest) and use caution when placing the person in a cruiser

F. Ongoing Investigation

Ongoing investigations of missing persons with AD/D should include, but should not be limited to, the following:

1. Requests for the release of dental records and fingerprints, if available.
2. Contact with hospitals and the coroner or the medical examiner's office as appropriate for injured or deceased persons fitting the description of the missing person.
3. Continuance of on-going contact by the lead investigator with the missing person's closest relative or responsible party and the assigned dispatcher concerning progress of the investigation.

G. Recovery of Missing Persons and Case Closure

1. Upon location of a missing person, all agencies and information systems previously contacted for assistance shall be notified or updated.
2. Missing persons and their caregivers shall be questioned to establish the circumstances surrounding their disappearance and how future incidents might be prevented.
3. The case report shall include a detailed report on the person's whereabouts, actions and activities during the investigation.
4. After Action Reports (AARs) shall be prepared, and a post-incident briefing shall be conducted to establish Lessons Learned.
5. In cases involving licensed care facilities, officers shall ensure that:
   a. The facility has taken proper precautions to prevent future incidents.
   b. Proper reports have been filed to the facility's chain of command – state accrediting agencies, corporate office, insurers, and others.
6. Where indicated, follow-up action shall include filing an abuse and neglect report with the appropriate state agency.
7. Where indicated, criminal charges shall be filed with the prosecutor's office.
8. In cases of death, investigative personnel shall follow-up with the coroner's office in determining the cause of death and identifying available evidence.

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Appendix A
Information for Families Caring for Individuals with AD/D

1. Research available identification and tracking systems and encourage use.
2. Install double-sided locks or disguise locks on doors to visually deter the person from using them.
3. Disguise exit doors in the home with curtains, wrapping paper, posters, or other visually distracting objects.
4. Place bells on doors and windows.
5. Remove the person's car if he or she still owns one, and hide keys to other cars in the household.
6. If possible, establish relationships with neighbors and exchange contact information in case of emergency.
7. Establish a schedule and follow it consistently to avoid the person leaving to seek something – food, bathroom, and so forth to avoid the person becoming agitated by a schedule disruption.
8. Prevention strategies and suggested community outreach:
   Since searches for missing persons with AD/D are expensive and exhaust many resources, it is advisable to implement prevention techniques within the community:
   a. Provide families caring for persons with AD/D in the home with information outlining steps to take to prevent the individual from going missing.
   b. Establish a voluntary registry program for at-risk persons:
      (1) Offer the program at community events, and use both uniformed and civilian volunteers to solicit people to register.
      (2) Include fingerprints, recent photos, several contacts such as neighbors, medical needs, routes, familiar places, and so on.

Alzheimer's Aware

Recognize. React. Respond.

A Guide for Implementing a Law Enforcement Program to Address Alzheimer's in the Community

CPSJ
Center for Public Safety and Justice
University of Illinois

BJA
Bureau of Justice Assistance
U.S. Department of Justice

Table of Contents

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ALZHEIMER'S AWARE
Recognize. React. Respond.

A Guide for Implementation of a Law Enforcement Program to Address Alzheimer's in the Community

Introduction

Today's headlines are all too often riddled with stories of missing aging seniors who have wandered off, sometimes unaware that they are in potentially dangerous situations or become lost and are unable to find their way back to their residence. For instance, the high profile cases like Ronald Westbrook, a 72-year-old man with Alzheimer's disease, who was shot by a neighbor who mistook him for a burglar. Authorities stated that Mr. Westbrook was disoriented and possibly suffering from exhaustion as he wandered his neighborhood in Chickamauga, Georgia in the early morning hours. Mr. Westbrook rang the doorbell and repeatedly jiggled the front door handle of an area home, prompting a confrontation with the homeowner who shot and killed him (Caufield, 11/29/13).

Consider, cases such as the one where police repeatedly used a Taser on a person with Alzheimer's because he became agitated and was confused and officers may not have been provided training to equip them with the skills and strategies to appropriately interact with a person diagnosed with Alzheimer's disease or other form of dementia (Vankin, 2013), to other local reports such as Vinny DiNatale, of Marshfield, Massachusetts, who went for a walk and didn't return. His wife contacted the Marshfield Police Department and informed them that her husband, who was diagnosed with Alzheimer's, was missing but was enrolled in the SafetyNet™ by LoJack® service. Officers immediately began a search eventually finding him in a remote area, close to a river, trapped in a patch of briars and unable to get out (Boston Herald, 5/23/12).

While Vinny's story had a happy ending, many others do not. The frequency of such stories underscores the importance of ongoing efforts to prevent wandering from ending in tragedy by improving law enforcement's approaches when encountering or searching for someone with Alzheimer's disease. These stories also highlight the importance of law enforcement agencies' need to work in partnership with the communities they serve to develop a holistic community approach to increase awareness of Alzheimer's and other forms of dementia; prevent those diagnosed with Alzheimer's from wandering; and work effectively to locate a missing person with Alzheimer's.

Never before in American history has our population included so many people 65 years of age or older; 40.3 million Americans, an estimated 13% of the population, according to the U.S. Bureau of the Census. This number is expected to more than double to 89 million by 2050. The 2010 U.S. Census indicates that for the first time in history, the number of people aged 65 and over are becoming an increasing larger portion of the population than the younger segments.

According to the National Institute on Aging' *Alzheimer's Disease Fact Sheet*:

"Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks. In most people with

Alzheimer's, symptoms first appear after age 65. Estimates vary, but experts suggest that as many as 5 million Americans age 65 and older may have Alzheimer's disease.
"Alzheimer's disease is the most common cause of dementia among older people. Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities, to such an extent that it interferes with a person's daily life and activities. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of daily living." [1]

Experts estimate that approximately 500,000 new cases occur each year. It is projected that by 2050 as many as 16 million Americans will develop Alzheimer's. Some of this number may be younger than 65. The *Alzheimer's Fact Sheet* says, "Early-onset Alzheimer's is a rare form of the disease. It occurs in people age 30 to 60 and represents less than 5 percent of all people who have Alzheimer's disease. Most cases of early-onset Alzheimer's are familial Alzheimer's disease, caused by changes in one of three known genes inherited from a parent."

As the nation's population continues to age, there will be more cases of Alzheimer's disease and therefore, more and more opportunities where those with Alzheimer's or other forms of dementia may come in contact with local law enforcement and public safety officials.

Law enforcement could become involved with individuals with Alzheimer's and their caregivers under a variety of every-day circumstances. Below are a few examples of behaviors or situations that could get the attention of law enforcement:

- ✓ Exhibiting erratic driving or breaking general rules of the road
- ✓ Crossing a road way or walking through traffic seemingly unaware of the danger
- ✓ Wandering with a dazed/lost like appearance
- ✓ Sitting in a car along the side of the road *(perhaps the car is out of gas)*
- ✓ Being out of place in a particular situation *(on a hiking trail/park late at night)*
- ✓ Inappropriately dressed for the situation or weather *(not wearing a coat in winter, or inappropriately barefoot)*
- ✓ A call to police regarding missing items or a "*break-in"*
- ✓ Inability to follow or understand simple requests *(May I see your driver's license and car registration, please?)*
- ✓ Difficulty interacting appropriately with others
- ✓ A domestic violence or physical abuse call that turns out to be a situation with a caregiver and an individual with Alzheimer's disease
- ✓ A shop-lifting accusation, *"stealing"* from local businesses but actually believing they paid for the item or that the item is already theirs

[1] National Institute on Aging, U.S. Department of Health and Human Services*: Alzheimer's Disease Fact Sheet,* NIH Publication No. 11-6423 (2011) http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet

- ✓ Responding to a call for a welfare check and having concerns about abuse, neglect or domestic violence, based on observations

Whatever the situation, it can be difficult for an officer to know what to do, and how to address the problem, and, as the world's population ages, these types of situations will only increase in frequency and will impact all law enforcement agencies at some point or another. Many law enforcement agencies across the nation are already working to increase positive outcomes when someone with Alzheimer's or other form of dementia is reported missing, or when an officer encounters someone with Alzheimer's, or a caregiver, during the normal course of their duties, through specialized trainings, resources and policy development which may include:

- ✓ Recognizing the signs of Alzheimer's disease
- ✓ Learning best practices in approaching and communicating with persons who have Alzheimer's
- ✓ Being aware of situations where an officer might encounter individuals with Alzheimer's and effective ways to respond during those interactions
- ✓ Insights and best practices in conducting searches for missing persons with Alzheimer's – *which is different than the manner one would plan or conduct a search for other missing persons*

Alzheimer's Aware – Program Overview

"Alzheimer's Aware" is a national initiative funded by the United States Department of Justice, Office of Justice Programs - Bureau of Justice Assistance. Alzheimer's Aware provides a variety of practical resources and tools that can be used by any law enforcement organization – or other interested group – that is working to increase positive outcomes during interactions with persons with Alzheimer's disease, particularly when related to the issue of wandering.

These resources and tools can be used to assist in the development and implementation of a community educational campaign by, or n partnership with law enforcement. The resources have recommendations for developing a strategic plan with practical action steps and activity implementation, in order to develop a holistic community approach to responding in crisis situations, involving persons with Alzheimer's disease, as well as increase awareness of Alzheimer's and other forms of dementia.

In order to reach the goals and objectives of increased awareness, appropriate response and interactions and improved outcomes as related to Alzheimer's disease and wandering, the national Alzheimer's Aware initiative is built around three (3) over-arching areas of focus:

- Law Enforcement Engagement
- Community Involvement
- Public Information / Awareness

All three focus areas center on an understanding that ***awareness*** – both at the law enforcement and community level – needs to be increased in order to improve the safety and well-being of these individuals, their families and the community as a whole. The following provides a more detailed description of the three focus areas.

Program Development

Law Enforcement Engagement

While most people understand that an individual with Alzheimer's will have memory loss and an inability to recognize persons or landmarks or other things that would be familiar to someone without the disease, persons with Alzheimer's can also be irrational, confused and even combative because of their perceptions of where they are, what they are doing and what is happening around them.

Law enforcement officers may come in contact with persons with Alzheimer's disease or other forms of dementia in a number of different types of situations and, having the ability to identify that a person who initially seems to be coherent may actually be confused and at-risk, may make the difference in what could become a potentially life threatening situation. After agency leadership has made a commitment to address the issue, there are four (4) critical areas on which law enforcement should focus its attention:

Officer and Staff Training

There are currently a number of options for training and the Department of Justice continues to work to develop additional types and avenues to increase those opportunities. The following is a list of organizations that currently provide some type of training for law enforcement on the basics of Alzheimer's disease and the impact of the disease. Some of these trainings are offered free of charge, others may involved fees. This is not an all inclusive list and additional training opportunities may be available through local organizations in your area that work with the elderly or health care providers and systems. Examples of trainings we are aware of include, but are not limited to:

International Association of Chief of Police (IACP)

IACP currently has 2 different types of training available to law enforcement agencies: A 1-Day, Direct Training Program and, a 2-Day Train-the-Trainer Program.

1-Day, Direct Training Program

The IACP Alzheimer's Initiatives training program, *Responding to Alzheimer's Disease: Techniques for Law Enforcement and First Responders*, is a program dedicated to providing public safety administrators, law enforcement officers, supervisors and executives, firefighters, EMS, EMT, and others from the first responder community with the most current Alzheimer's and dementia training available. The one-day program is offered at **no-cost, and f**eatures in-depth instruction to help a department enhance its capacity to handle calls involving people with Alzheimer's disease and related dementia. The program offers its training seminars to law enforcement and first responders nationwide. As a result of this training, participants will:

- Have a better understand Alzheimer's disease
- Be able to identify situations first responders might encounter persons with Alzheimer's disease
- Distinguish symptoms of Alzheimer's disease from other conditions
- Learn techniques to effectively question and interview persons with Alzheimer's disease to determine the most effective response
- Communicate and collaborate with caregivers
- Engage community resources
- Establish protocols for search-and-rescue specific to this population

IACP Train-the Trainer Program

In addition to the one-day, on-site training program, IACP now is offering a **two-day** Train-the-Trainer program for selected participants and experienced trainers who will continue to support and deliver the one-day training program. Positions in the two-day Train-the-Trainer program are limited. Trainers/facilitators will be drawn from those with law enforcement and/or first responder backgrounds, and those with community experience and expertise in the area of Alzheimer's disease and dementia. Training and facilitation experience is preferred. Participants in the Train-the-Trainer will learn and demonstrate parts of the Responding to Alzheimer's disease workshop and receive feedback. **PARTICIPANTS CHOSEN FOR THIS TRAINING WILL BE EXPECTED TO CONDUCT AT LEAST ONE RESPONDING TO ALZHEIMER'S DISEASE WORKSHOP FOR YOUR AGENCY OR COMMUNITY WITHIN 90 DAYS OF COMPLETING THE PROGRAM.** IACP will provide guidance, materials and support for local workshops but costs of trainer time and travel, training space and equipment, and participants' time and travel are born by local agencies and/or individuals. Persons selected to attend a training will be notified of enrollment prior to the start date for the course. It is anticipated that several agencies across the country will become trainers for this topic and may be able to assist training officers in other nearby jurisdictions.

IACP Roll-call Training Videos

The IACP's Alzheimer's Initiatives training program has developed 4 short training videos which discuss various situations that law enforcement and first responders may encounter a person with Alzheimer's disease or dementia. The videos cover the topics - Driver Assessment (traffic stop); Missing Person (on foot); Missing Person (by car); and Overview of Search Protocol. Each video includes a companion discussion guide and are available either for download from the IACP web site at http://www.theiacp.org/Alzheimer-Training-Video or on a DVD that can be ordered by emailing alzheimers@theiacp.org.

Alzheimer's Association

Almost every part of the continental United States, Alaska and Hawaii are covered by a Chapter of the Alzheimer's Association. Many local chapters will provide direct training to law enforcement and first responders on the disease and its impact. Contact your local chapter for information on their educational offerings. The Alzheimer's Association is on the web at www.alz.org. Additionally, the Alzheimer's Association has an on-line training available for first responders that was created with the assistance of first responders. It is an interactive training with video scenarios and other tools that is available 24/7 at: www.alz.org/care/alzheimers-first-responder.asp.

National Council of Certified Dementia Practitioners (NCCDP)

National Council of Certified Dementia Practitioners is an organization open to health care professionals, front line staff and First Responders who qualify for CDP® certification . The Council was formed to promote standards of excellence in dementia and Alzheimer's disease education to professionals and other caregivers who provide services to dementia clients.

The NCCDP seminar is an 8 - hour training designed for First Responders, Law Enforcement, EMT's and Fire Fighters and is additionally recommended for Trainers who are responsible for First Responder Training. The Train the Trainer seminar provides over heads, power point, text book, video and hand outs.

The NCCDP course includes the modules on: Introduction to Dementia (Diagnosis, Prognosis, Treatment), Communication and Feelings, Depression and Repetitive Behaviors, Paranoia, Hallucinations, Wandering, Hoarding, Aggressive Behaviors, Catastrophic Reactions, Intimacy & Sexuality, Dementia & Driving, Activities, Staff and Family Support, Recognizing Abuse and Neglect in The Home, Diversity and Cultural competence, Spiritual Care and End of Life Issues.

Each participant receives handouts about each module. Upon completion of the seminar, each person receives a certificate of attendance. In order to accommodate all shifts, the NCCDP can provide training and dates to accommodate the entire force.

Local Alzheimer's support organizations

Check with local health care systems, Alzheimer's providers, hospitals or support organizations in your area to determine if they may offer educational courses on Alzheimer's disease. For example, in a sub-grantee pilot site in Arizona, Banner Health's Alzheimer's Institute, a Center of Excellence in the Banner Health System, has been working with the local law enforcement agency to develop a training program to train all of the sworn officers in the agency.

Agency Policies and Procedures

- Review existing agency policies and procedures , to ensure that they appropriately address and take into account contacts with persons with Alzheimer's or other cognitive disabilities and take necessary steps to adjust them accordingly and as appropriate, ensure that all future policies and procedures have been adjusted accordingly.

- Adopt standard policy for addressing reports of missing persons with Alzheimer's disease. The International Association of Police has researched and developed an Issue s and Concepts Paper, along with a Model Policy related to Reports of Missing Persons with Alzheimer's disease and related dementias. The policy provides an overview of the disease and addresses a variety of issues and situations related to law enforcement practice and the disease. (IACP model policy can be viewed at http://www.theiacp.org/MPAlzheimers.)

- Development, implementation or adjustment of local projects / operations related to at risk populations. Many law enforcement agencies currently have programs that are related to seniors, such as participation on groups addressing elder abuse or neglect, driver education or assessment classes held for senior citizens, or community advisory councils that provide input for the department. With some minor additions or adjustments to programs currently in place program, additional information can be added or adjusted to address Alzheimer's related issues.

At-Risk Population Registry

- Development and implementation of a local registry program
- Promote the of use of a national registry
- Encourage the use of locative device technology, when appropriate

Many local law enforcement agencies have developed and implemented their own local registries that are housed or maintained in the area – either at the law enforcement agency or with a local community

organization – for persons who are at risk of wandering or those who have already experienced an incident of wandering. Having a registry can be a relatively easy project and may only involve a few changes to the current CAD system.

One national registry program, the MedicAlert® + Alzheimer's Association Safe Return® program, through a direct connection to law enforcement's RISS (Regional Information Sharing System) makes information, on more than 200,000 individuals with Alzheimer's disease who are currently enrolled in the program, available to any law enforcement agency. This program does not require any participation or equipment to be based at the local law enforcement agency in order to get community members enrolled. Increased use of this registry by individuals would be an easy and relatively inexpensive way to have valuable information and resources available to law enforcement when an individual with Alzheimer's wanders. The only requirement of the agency is access to RISS or FBI's LEO (Law Enforcement Online). Other programs exist and may be included as an additional component of locative technologies.

Encourage the Use of Locative Technologies

As the world's use of technology expands, a variety of electronic tracking and locative devices have been developed for use in tracking not only property, but also persons. Devices vary in both the way they are used and the type of technology. Some devices dating to the Viet Nam War, use radio frequency transmitters and receivers; others newer cell phone technology and yet others are as simple as a hard-wired, electric door alarm.

The use of these devices has proven successful in not only preventing at-risk persons from wandering or leaving a safe environment, but have saved the lives of many individuals who have wandered or become lost and were able to be located before anything serious happened to them. A variety of devices are described in the Locative Technologies brochure, published by the IACP. The use of a locative device should be strongly encouraged for those who have a history of wandering. Familiarity with the various types of devices is critical to successful use, as effectiveness and usability vary with terrain, etc. Some of the devices require specialized training for those conducting searches to locate a missing person.

Community Involvement

Just as law enforcement personnel need to be educated to their potential involvement and interaction with persons with Alzheimer's disease, the community – both those who are currently touched in some way by this disease and those who have not as yet realized that Alzheimer's can impact them- needs to be informed about the ways that Alzheimer's can have an impact on them and how they can effectively handle situations in which they have contact with a person with Alzheimer's. Some suggestions for involving and educating the community include:

- Establishment of a community or senior citizen liaison committee (or alteration to currently existing local advisory committees) to aid the local law enforcement agency and get community input into programming.

- Designation and advertising of a "Senior / Elder Liaison Officer" at the law enforcement agency to address issues impacting senior citizens in the community, such as driving or fraud and abuse issues.

- Partnering with a local healthcare system or community organization to implement an Emergency Plan Safety Program so that emergency information regarding caregiver continuity can be in a

recognizable place for first responders. (While some seniors with Alzheimer's have caregivers, a crisis could occur if the caregiver suddenly has a health emergency, or if a person with Alzheimer's is taken in an emergency situation by first responders and is unable to communicate who should be called and alerted to the situation.)

- Use volunteers to supplement / help to focus on senior issues. Obviously, the costs involved in program development and implementation have an impact on what can be accomplished for this – or any program. The use of volunteers in programs that might connect Alzheimer's patients or caregivers with other community services or check on a repeat wanderer's welfare is a good use of volunteer time.

  For example, the Alzheimer's Aware pilot site at the Lee County, Florida Sheriff's Office developed a project called *WeCare*, that involved trained volunteers checking on persons who had been identified as having Alzheimer's or other form of dementia that might indicate a need for some type of welfare check.

- Establish a page or tab on the law enforcement agency website to provide general information on Alzheimer's disease, with links to agencies at the federal, state and community levels, for additional information, resources or services.

Public Education Regarding Alzheimer's Disease

There are a significant number of educational opportunities available across the United States related to Alzheimer's disease. With just a few exceptions, the Alzheimer's Association has chapters that cover each state and provide education and support for persons with Alzheimer's and their caregivers. In addition to local trainings and educational opportunities, the national office of the Alzheimer's Association has online training that can be accessed by anyone. Also, other local organizations, research foundations and resource centers offer education and training on Alzheimer's related issues.

Getting the message out to the community that everyone has the potential to be impacted by this disease – whether they know it or not – is key to engaging community members and organizations in the effort to address Alzheimer's disease. With little effort or funding, a local law enforcement agency can develop a plan or strategy to link the variety of persons impacted by the issue to educational opportunities in their local area, as well as resources that might be available.

Specifically, Alzheimer's Aware initiatives attempt to increase awareness and provide educational opportunities in the community. Community relations staff at law enforcement agencies can increase awareness by doing community presentations about the disease, the interaction with law enforcement, and what steps caregivers or members of the community can take to have a positive outcome for persons with the disease. The Alzheimer's Aware initiative has developed a community presentation that can be used to update and engage community groups and organizations, including, but not limited to:

- Public safety personnel, including first responders (fire, EMS, etc.) and staff from regulatory and utility agencies (e.g. water & electric services; code enforcement, etc.)

- Families and caregivers of persons with Alzheimer's disease

- Health Care Professionals (general practice physicians or medical associations, EMT's who provide care to caregivers of Alzheimer's patients, etc.)

- Local businesses, industries and retail locations that may come in contact with persons who have wandered, are confused and need assistance or who may be confused about whether or not they have purchased items

Conclusion

The Alzheimer's Aware Initiative can be locally implemented at a relatively low-cost but with the potential to have a significant impact when it comes to the welfare and safety of those in the community with Alzheimer's disease or other form of dementia. The initiative has a variety of resources, best practices and practical tools which can be used free of charge and can be adapted to the needs and abilities of the local law enforcement agency and community.

Implementing a local Alzheimer's Aware initiative starts with the recognition that Alzheimer's will impact your community and your agency – if not now, at some point in the near future. ***Recognize*** that the issue is important and is coming. ***React*** to the need for leadership in the area and the need for consideration of the impact your agency can have on the growing population of older Americans in communities all across the country. And, ***Respond*** by making your agency Alzheimer's Aware and ready to respond appropriately.

RECOMMENDED STEPS
For Law Enforcement Agencies
PROGRAM DEVELOPMENT AND IMPLEMENTATION
OF *ALZHEIMER'S AWARE*

1. **Secure a leadership commitment** to address improving outcomes related to Alzheimer's disease and law enforcement. How the staff reacts and considers this effort will be greatly impacted by the commitment to the program by agency leadership.

2. **Appoint a lead staff person** for the local agency Alzheimer's Aware effort. Having an individual who can shepherd activities and programmatic efforts throughout the agency is key to success.

3. **Establish an internal team of varying ranks and positions** to discuss and plan for policy review and modifications, training assessment and planning, as well as community engagement strategies. This internal team comprised of front-line officers, administration and non-sworn staff and department volunteers, should review any prior calls for service involving persons with persons with Alzheimer's and assess response and outcomes. Including dispatch, on the internal team, brings an important perspective as they are generally the first contact family, friends, patients or others may have when contacting the law enforcement/public safety agencies.

4. **Appointment of a community/local advisory committee** or, use of a current agency advisory group, such as a senior advisory committee or community advisory committee, with added members or specific community agencies that can represent various community partners with regard to this initiative. Regular engagement of advisory committee members and other community groups or agencies is critical in successfully implementing your strategic plan.

   Example: The Alzheimer's Aware pilot site at the Mesa, Arizona Police Department, in collaboration with their advisory committee, developed innovative strategies to distribute Alzheimer Aware Adult ID Kits among hair salons and other businesses frequented by the aging population in the area.

5. **Commitment to training all officers and non-sworn staff** on the basics of Alzheimer's disease and effective ways to approach those who are displaying symptoms or behaviors indicative of the disease. This training can be multi-layered using available training options. Trainings that come highly recommended are::

   a. IACP's Alzheimer's Initiatives 8-hour in-house training, Responding to Alzheimer's Disease: *Techniques for Law Enforcement and First Responders*

   b. The University of Illinois - Center for Public Safety and Justice Alzheimer's Aware: *Roll Call Training for Law Enforcement* 4-part series

   c. IACP's Alzheimer's Initiatives Roll-call training videos covering various situations that law enforcement might encounter

6. **Convenient on-sight access to resources** for local officers' non-sworn personal and volunteers to use when interacting with persons with Alzheimer's disease, their caregivers and the community.

Many documents and resources have been produced to assist with identifying possible cases of dementia, what steps should be taken when an incident occurs, the "do's and don'ts" of how to communicate with someone with the disease, as well as resources to provide to caregivers such as the Adult ID Kit. These resources are available free of charge via the International Association of Chiefs of Police website and through the Center for Public Safety of Justice.

7. **Review of department missing persons and other applicable policies** with consideration to policy modification, as needed, to include special accommodations that can be used when dealing with a person with Alzheimer's disease. IACP has published an Issue Paper and Model Policy on Alzheimer's disease. The IACP Model Policy is specifically related to missing persons with Alzheimer's disease but could be incorporated into other existing policies. Additionally, information identified in the Model Policy relates to the behaviors and hallmarks of the disease which may have an impact on other policies, such as use of force, handcuffing, domestic violence or others, all of which should be reviewed.

8. **Development and implementation of a local public information campaign** to raise awareness among community members and local businesses about Alzheimer's disease, its impact on the community and how the community can play a key role in instances of wandering and during day-to-day interactions with individuals with Alzheimer's disease or dementia. Consideration should be given to the delivery of the *Alzheimer's Aware Recognize, React, Respond*: *Caregivers and Community Awareness Workshop* developed by the Center for Public Safety and Justice. Law enforcement agencies are requested to do public presentations to community groups, including senior related groups or community service organizations. The Caregivers and Community Awareness Workshop would be a presentation that could be made to raise public awareness.

   As a part of an effort to raise awareness, an Alzheimer's Aware pilot site at the Lee County, Florida Sheriff's Office, in collaboration with their community partner, contacted the local medical community via letters to ensure that physicians seeing patients understood the importance of early diagnosis and planning by patients and family members. A key area where healthcare professionals can be of critical support, to caregivers, is determining when the patient should be assessed for their ability to operate a motor vehicle. Often this decision is easier to accept with healthcare professional involvement, avoiding the sole burden and ramification of the decision being the family member or caregiver's responsibility.

   Development and implementation of a local "registry" to allow the law enforcement agency to more quickly respond to and be able to identify persons in their community with Alzheimer's disease or related dementia, during routine calls for service or during a "wandering" incident.

   Local registries have been developed by a number of law enforcement agencies across the country. In some instances, the law enforcement agencies have formed partnerships with a local community provider or service agency to assist them in collecting and proofing pertinent data that is then either maintained in the CAD system or a system designed and maintained by dispatch to allow for easy and immediate access to the data. Examples of minimum data set to be collected and maintained include information on the Alzheimer's Aware Adult ID Kit Brochure of the Mesa Police Department (http://www.mesaaz.gov/police/PDF/AdultIDKit.pdf) or the Alzheimer's Alert project by the Prescott Police Department (http://www.prescott-az.gov/_d/alz_alert_form.pdf).

Some programs include use of identifying jewelry with numbers that coincide to registry files, others involve electronic locative devices, or other equipment. A registry can be designed to fit the needs and budget of the agency.

When developing a local registry, care must be taken to address issues of confidentiality of data submitted to the Department and that the data would not be considered "public information".

A local registry can also encourage participation in a national registry for persons with Alzheimer's. The local registry should be maintained in a safe environment, that allows for easy search capabilities using a variety of data fields and should include a recent photograph of each person included in the registry.

10. Encourage the use of electronic monitoring and/or locative devices by those individuals with Alzheimer's disease who have a history of wandering. The agency should research the functionality and performance of the various technologies in their area and provide information to families and caregivers, in an effort to ensure the safe return of the person, should they wander again.

9. **Review of ongoing local projects/operations** to determine where there exists commonalities to Alzheimer's at-risk populations and where information to increase awareness and preparedness can be effectively distributed community-wide. For example the distribution of Alzheimer's Aware Adult ID Kits through participation in senior health fairs, driver assessment courses, a local Meals-on-Wheels program or through the faith-based community.

10. **Development and collection of statistics** illustrating the impact policy and practice changes have on law enforcement interactions, with individuals with Alzheimer's disease, their caregivers and the local community. Data collection should also measure general awareness by the community, proactive preparedness by caretakers and registry use. It should also include measures to demonstrate the project's impact on sworn and non-sworn agency employees' behaviors, attitudes and overall awareness of available Alzheimer's Aware resources and the use of resources and tools.

Anger, Frustration & Fighting

People with Alzheimer's or dementia can get confused, depressed, and angry. Their feelings and actions are sometimes hard for them to control.

They may hit and yell.

Don't take their words or actions personally.

Listen to what they mean, not what they are saying.

WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- be confused by
  - new places or people
  - something they see and don't know
- become frustrated because they can't
  - pull on a sweater
  - open a door
  - find a lost item like a purse, wallet or glasses
- be frightened or scared of
  - the shower or bath
  - a new place or person

WHAT CAN YOU DO?

Keep Things Simple

- try to match tasks and what you expect with what your person can do
- keep your home quiet and calm when you can
- speak slowly and try not to say too much at one time

Make a Change

- offer a treat like a cookie or some ice cream
- lead your person to a different room
- offer to watch a TV show or listen to music
- ask a question about a topic your person enjoys

Be Safe

- remove or lock away all weapons (guns, knives, etc.)
- back away slowly if the behavior is scary
- call 911 if you are afraid for your or someone else's safety

Enojo, Peleas y Desesperación

Las personas con problemas de memoria se confunden fácilmente. También pueden enojarse, gritar y hasta pegar. No se ofenda por lo que digan o hagan. Trate de comprender lo que están tratando de decir.

¿POR QUÉ PASA ESTE PROBLEMA?

La persona con Alzheimer se frustra porque:

- no puede abrir la puerta
- no puede vestirse
- no puede encontrar algo que perdió como el bolso, la cartera o los lentes
- no reconoce donde está
- desconoce a sus familiares

La persona con Alzheimer puede tener miedo

- del baño o la ducha
- de una persona o un lugar nuevo
- de su propio reflejo

¿QUÉ PUEDE HACER?

Recomendaciones

- mantenga el hogar tranquilo y calmado
- hable lentamente usando frases cortas y sencillas
- busque actividades que la persona con Alzheimer todavía pueda y quiera hacer

Cambie el ánimo de la persona con Alzheimer

- háblele de un tema agradable
- llévelo a otro cuarto
- ofrézcale algo para comer como fruta o un dulce
- mantenga la calma y trate de distraer a la persona con una actividad

Manténgase seguro

- ponga armas y cuchillos bajo llave
- si usted no se siente seguro, aléjese lentamente y pida ayuda
- si usted u otra persona están en peligro, llame al 9-1-1

EFFECTIVE COMMUNICATION WITH YOUR PATIENT ABOUT LOSS OF DRIVING PRIVILEGES

- Be EMPATHETIC. For many people, loss of driving can mean loss of independence.
- Reinforce MEDICAL DIAGNOSIS and importance of SAFETY.
- Stress the POSITIVES and offer ALTERNATIVES.
- Appeal to your patient's sense of RESPONSIBILITY.
- Reaffirm SUPPORT.
- Refer patient and family to the Alzheimer's Greater Los Angeles for additional information and support.

Dementia And Driving

WHAT HEALTHCARE PROFESSIONALS NEED TO KNOW

In the State of California, physicians and surgeons are required to report any patient with a disorder characterized by lapses of consciousness. This includes Alzheimer's disease and dementia.

By law, they must report drivers who have medical conditions or functional impairments that may affect safe driving ability. Reports must be made immediately to the local health officer, in writing. Reports must include the name of the patient, date of birth, and address (Health and Safety Code Section 103900).

The California Department of Public Health has a reporting form called the **Confidential Morbidity Report (CMR)** which helps facilitate the reporting process and fulfills mandatory reporting obligations. It is available online at http://www.cdph.ca.gov/pubsforms/forms/CtrldForms/cdph110c.pdf. Once the CMR is completed, it must be returned to the patient's local health officer.

For Additional Information

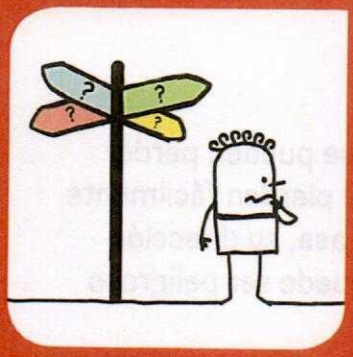
To locate your patient's local health officer, go to the California Health Officers Directory:
http://www.cdph.ca.gov/programs/cclho/Documents/CCLHOHealthOfficerDirectory.pdf

Alzheimer's Greater Los Angeles can provide information, emotional support, caregiving tools, and referrals for people with dementia, their families, and healthcare professionals.

Getting Lost

People with Alzheimer's disease or dementia can get lost outside of their home. Sometimes they wander away in a public place. They may go for a walk or to the store and not be able to find their way home. They may not remember their address or phone number.

Getting lost is scary and can be dangerous.



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- be confused... mainly in the afternoon or evening
- feel fearful ... home may not seem the same
- try to go somewhere they used to go often... work, church, *etc.*
- attempt to get away from noise or too much activity
- be bored – not having anything to do
- have a reaction to a new medicine

WHAT CAN YOU DO?

Be Prepared

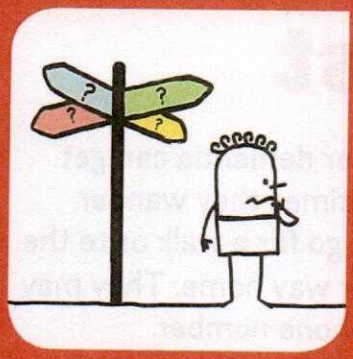
- get a MedicAlert® bracelet for your person with dementia
- sew or write his or her name and your phone number onto clothes
- don't leave him or her alone near an unlocked door
- ask your neighbors to keep an eye out and to tell you if they see your person with dementia outside alone or walking away from home
- help him or her exercise during the day... take a walk or dance to music
- put away purses, coats, keys, sunglasses... things that might make your person think about leaving
- close the curtains so he or she doesn't think about going outside

Make Home a Safe Place

- put child-proof locks on doors, gates, and windows
- place locks very high or low so your person with dementia can't see or reach the locks
- place a bell on doors, gates, or windows so you know if they are opened

Be Comforting

- offer food or do something that will take his or her mind off wanting to leave
- ask for help... folding clothes, making dinner, etc.
- sit quietly with him or her... listen to music or watch a TV show



¿POR QUÉ PASA ESTE PROBLEMA?

- Una persona con Alzheimer se puede confundir especialmente por la tarde y por la noche
- a veces puede ser una reacción a un medicamento nuevo
- tiene miedo–se siente inseguro al no reconocer donde está
- puede tratar de ir a trabajar o hacer algo que hacía antes
- quizás esté tratando de escapar del ruido o de la actividad en el cuarto
- está aburrido
- puede sentir algún malestar
- puede tener hambre, frío o necesita usar el baño

Perderse

Algunas personas con Alzheimer se pueden perder al salir de casa. Estas personas se pierden fácilmente y olvidan el camino de regreso a casa, su dirección o número de teléfono. Perderse puede ser peligroso para la persona con Alzheimer.

¿QUÉ PUEDE HACER?

Esté preparado

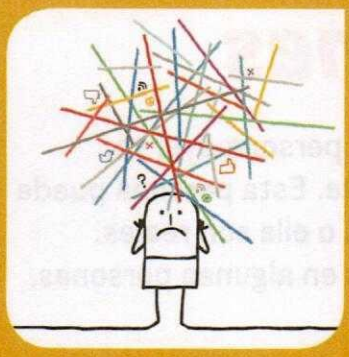
- obtenga un brazalete/pulsera de MedicAlert ®
- cosa o escriba el nombre de la persona con Alzheimer y un número de emergencia en la ropa
- no deje a la persona con Alzheimer sola o cerca de una puerta que no tenga seguro
- pídale a sus vecinos que le avisen si la persona con Alzheimer se sale a la calle
- si es posible, saque a la persona con Alzheimer a caminar o hagan algún tipo de ejercicio en casa
- guarde monederos, llaves y abrigos que puedan causar que la persona con Alzheimer quiera salir de casa

Mantenga el hogar seguro

- instale seguros a prueba de niños en puertas y ventanas
- cierre las cortinas para evitar que la persona quiera salir
- coloque los seguros en puertas y ventanas fuera del alcance de la persona con Alzheimer
- instale una campanita en la puerta para que suene cuándo se abra

Si la persona con Alzheimer se encuentra nervioso

- trátelo con cariño, y dígale "No se preocupe. Yo estoy aquí. Yo le ayudo."
- ofrézcale algo de comer o hagan alguna actividad juntos que le guste para distraerlo
- pídale que le ayude a doblar la ropa o preparar la cena
- siéntese en silencio con la persona con Alzheimer o escuche música agradable



WHY DOES THIS HAPPEN?

Your person with Alzheimer's or dementia might be:

- having a reaction to medicine
- taking the wrong amount of medicine
- going through changes in the brain due to the disease

Hallucinations

People with Alzheimer's or dementia can sometimes hear, see, smell, taste, or feel something that is not really there. They may talk to someone from the past who is no longer in the home or even still alive or is a pretend friend. This can alarm family and friends.

WHAT CAN YOU DO?

See a Doctor

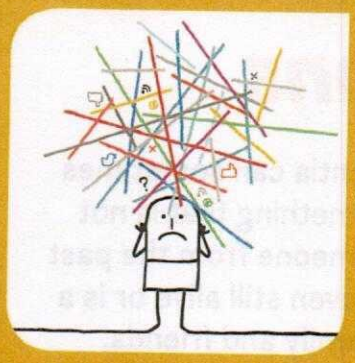
- visit the doctor to find out the cause (bring ALL medications with you)
- tell the doctor about every time you think this has happened (keep a log — day, time, and what was going on around the person with Alzheimer's or dementia)

Think About the Cause

- change the possible reason
  - if the person doesn't know who is in the mirror, cover the mirror
  - if things come out in the dark, turn on the lights or use a nightlight
  - if the TV or radio is confusing or scary, turn it off

Be Reassuring

- say things like "don't worry, I'm here and will take care of you"
- agree, don't argue, about whether what's happening is real... it is real to them
- involve him or her in something pleasant to distract them



¿POR QUÉ PASA ESTE PROBLEMA?

- Las alucinaciones pueden ocurrir por cambios en el cerebro causados por el Alzheimer que hacen que la persona vea las cosas diferente
- puede ser una reacción a algún medicamento
- puede estar tomando su medicina incorrectamente

Alucinaciones

Las alucinaciones es cuando una persona oye, ve, huele o saborea algo que no existe. Esta persona puede tener conversaciones que para él o ella son reales. El Alzheimer causa alucinaciones en algunas personas.

¿QUÉ PUEDE HACER?

Si nota alucinaciones, hable con el doctor

- lleve todas las medicinas a la visita con el doctor
- reporte los cambios de comportamiento, incluyendo cada cuándo y por cuanto tiempo sucede

Piense en lo que puede estar causando las alucinaciones

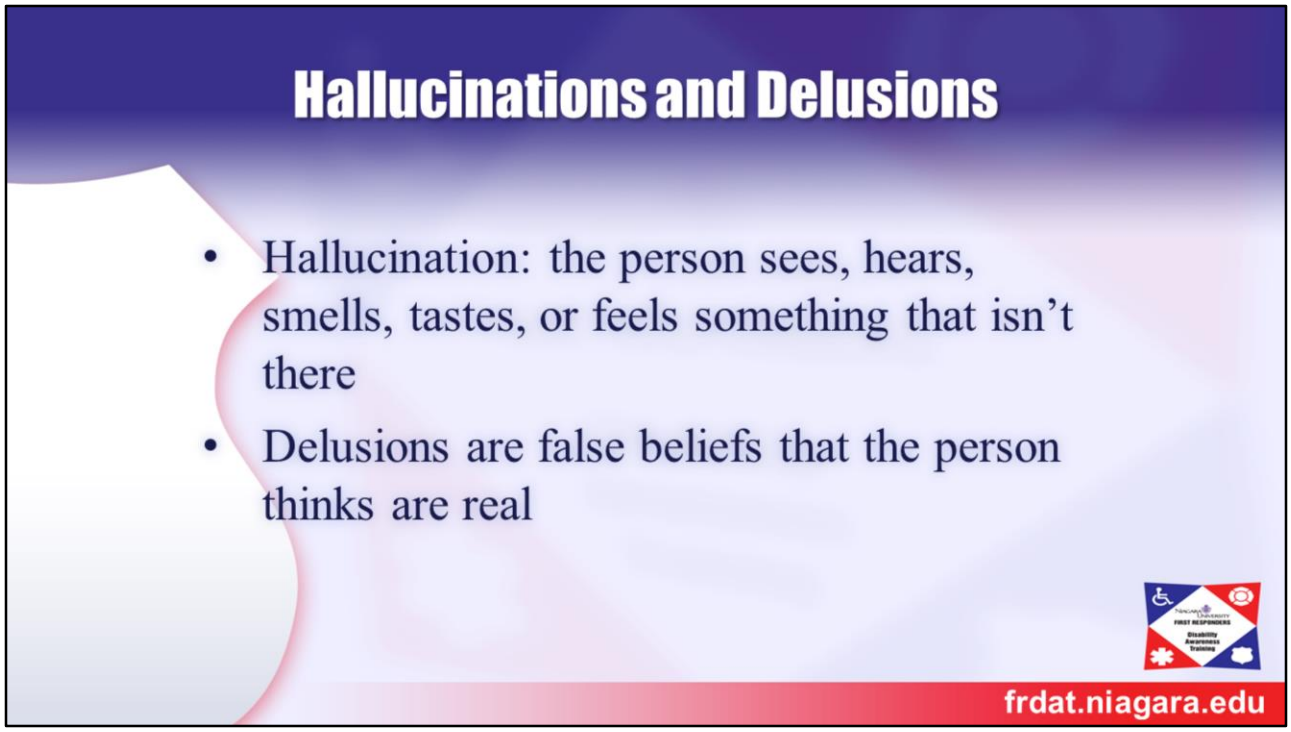
- cambie el ambiente
  - si la persona no se reconoce en el espejo, cubra el espejo con una sabana
  - si cosas salen en la obscuridad, prenda la luz o use una luz de noche
  - si la televisión o la radio lo esta confundiendo o asustando, apágelo

Tranquilice a la persona con Alzheimer

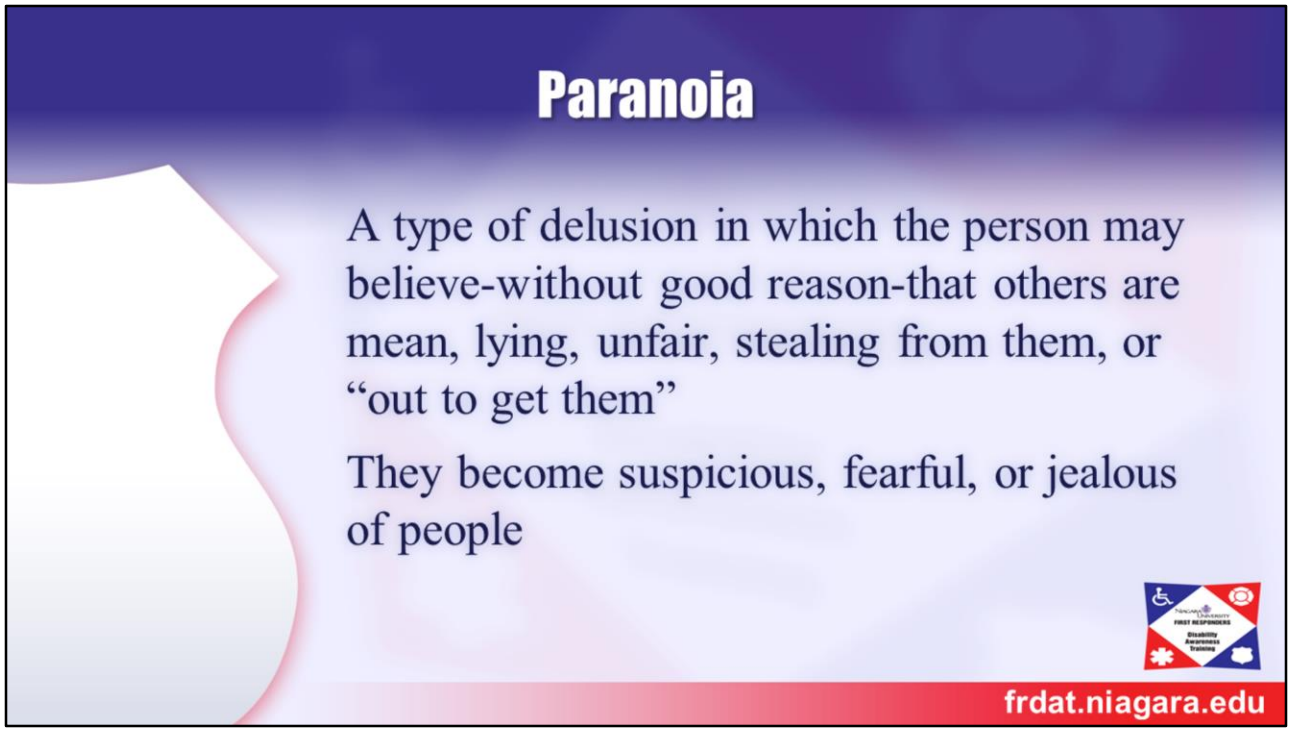
- diga, "No se preocupe. Yo estoy aquí. Yo le ayudo."
- no discuta. Lo que la persona con Alzheimer ve o escucha es real para él

Handouts:

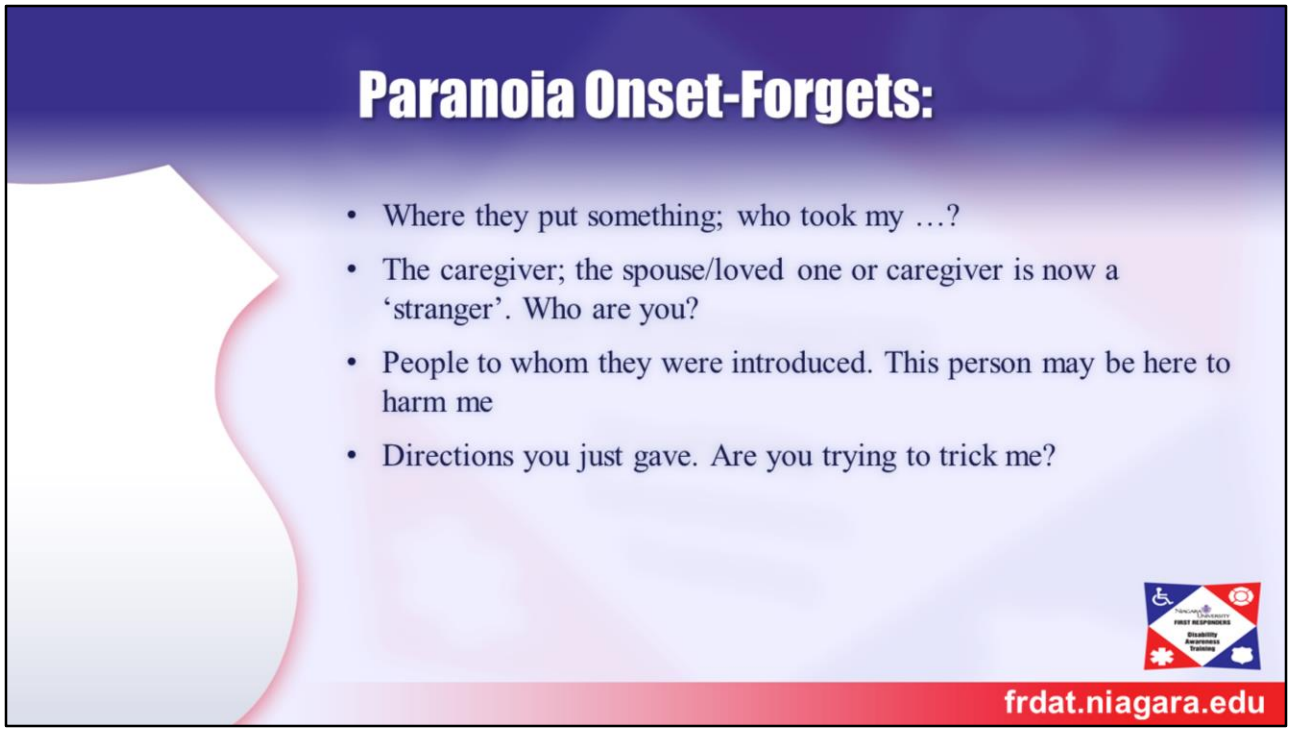
1. Preparing and Preventing Wandering
2. Keeping Home Safe
3. IACP's Alzheimer's Initiatives-Locative Technologies 101
4. Alzheimer's Aware-Adult Id Kit
5. Alzheimer's Aware-Informing the community on your department's website
6. Missing Persons with Alzheimer's Disease- Model Policy
7. Alzheimer's Aware Guide
8. Anger, Frustration & Fighting
9. Dementia and Driving
10. Getting Lost
11. Hallucinations



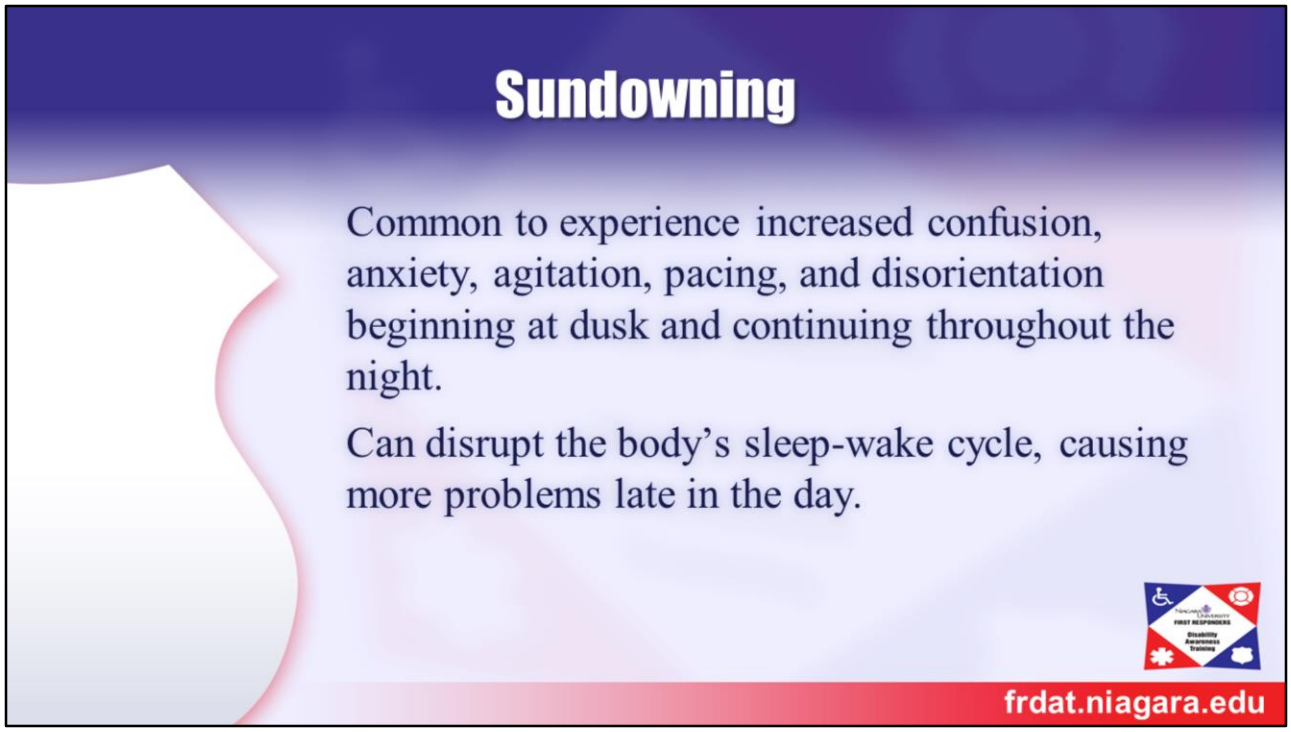
- As the dementia progresses, a person may have hallucinations, delusions, or paranoia
- Tips for coping with hallucinations and delusions:
- Do not argue with the person or try to convince them it is not real.
- Comfort the person if s/he is afraid. Let them know you are here to help.
- Distract the person. Moving to another room, going outside or changing the topic may help
- Turn off the TV, especially if something is on that may disturb them.
- Make sure they are safe and can not reach anything that could harm you or them.



- In person with Alzheimer's dementia, it is often linked to memory loss. It can become worse as memory loss gets worse.



- Will often times lead to a call for police presence
- I can not find my wallet so "this 'person' must have taken it" or "I've been robbed"
- There is a strange person in my house when it is actually their spouse or long time Personal Care Assistant
- Other possible calls to 911 would be for the noise outside or someone is on the premises. This could be kids playing next door, the mail carrier, or someone cutting their lawn.

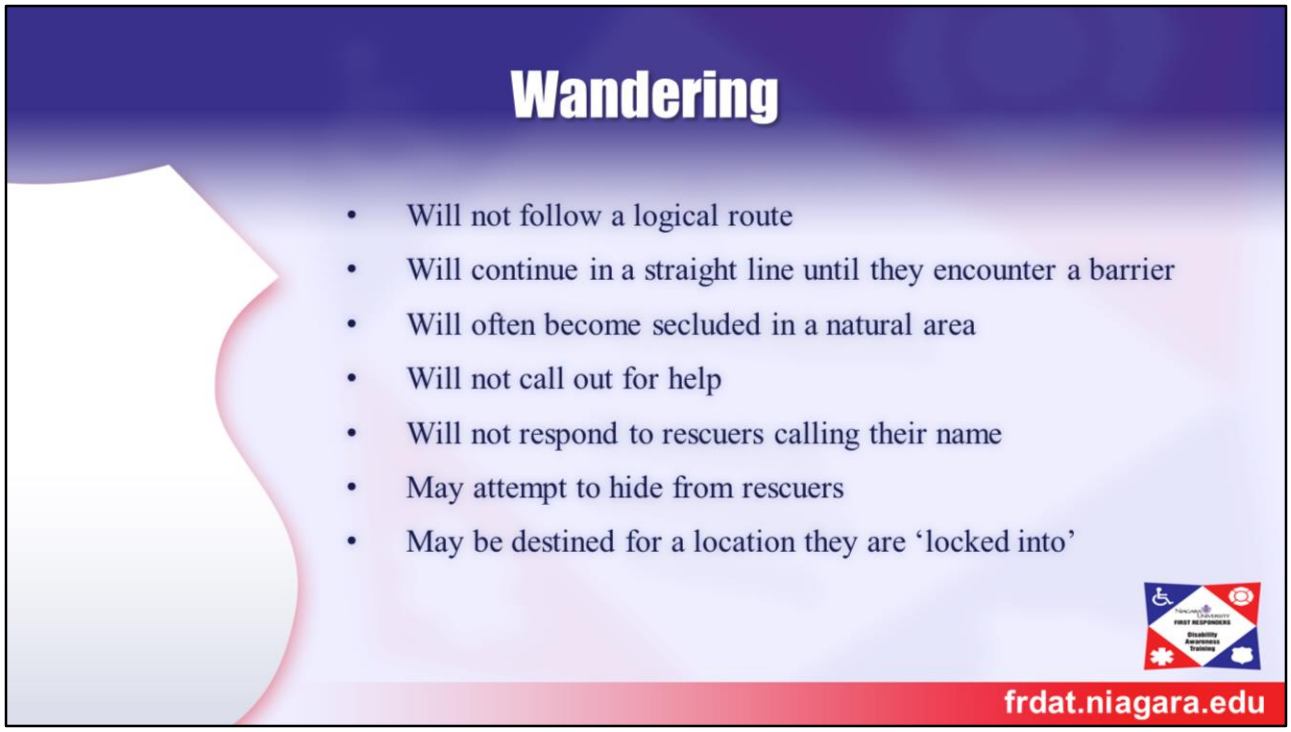


Some factors that may cause it are:

- Mental and physical exhaustion from a full day trying to keep up with an unfamiliar or confusing environment

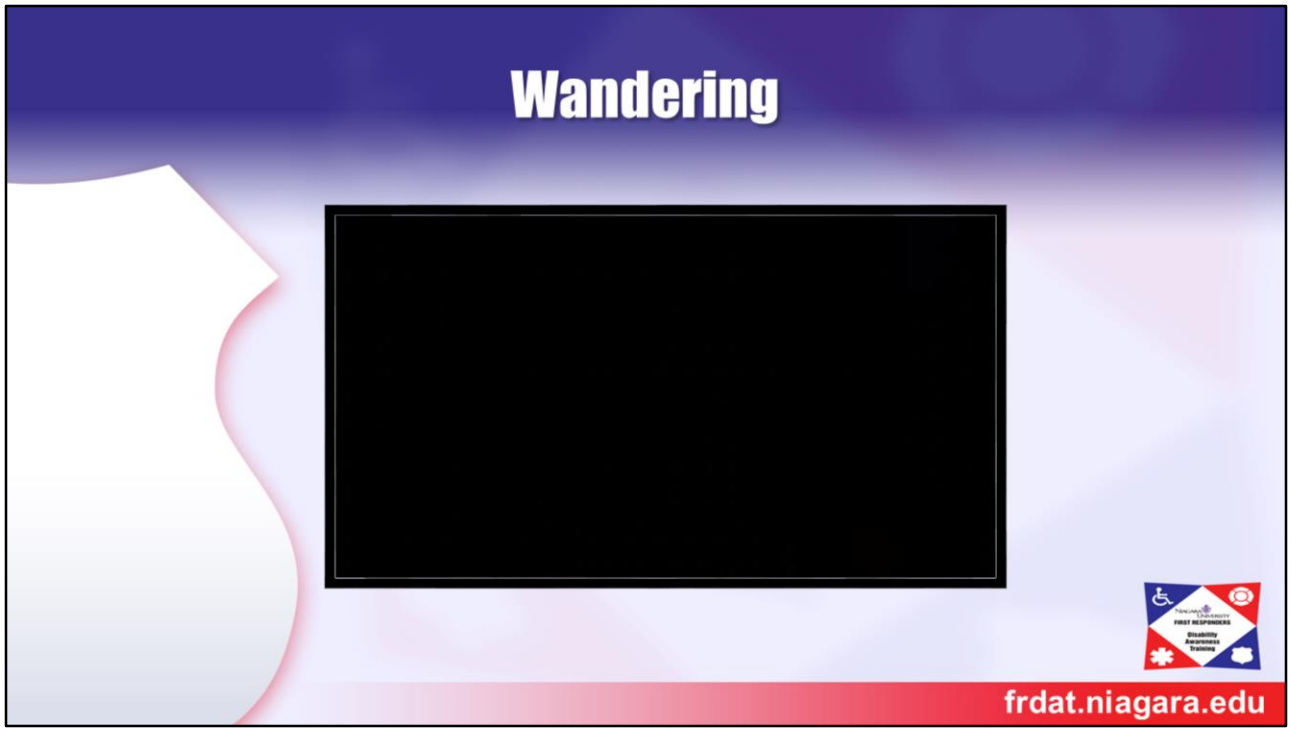
- Nonverbal behaviors of others, especially if stress or frustration is present, may be inadvertently transferred to the person living with AD.

- Reduced lighting can increase shadows and may cause the person living with AD to misinterpret what they see and, subsequently, become more agitated.

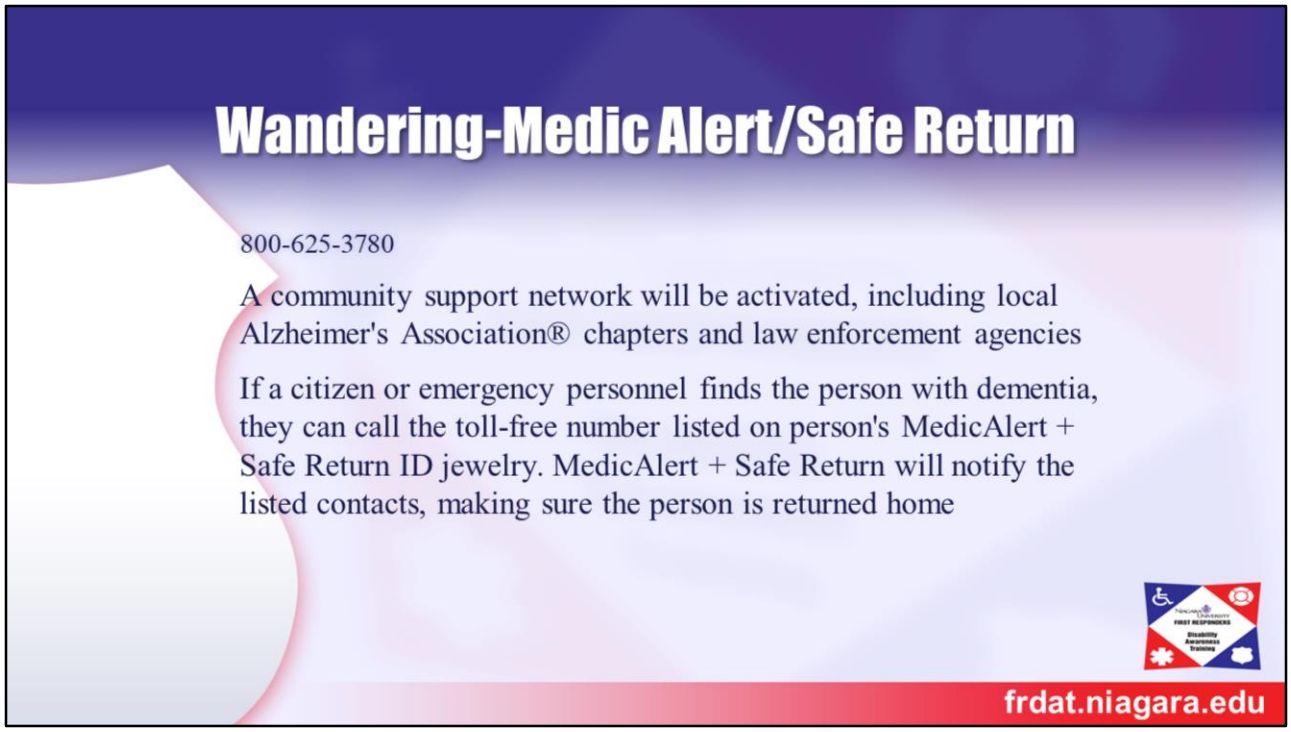


- Most likely typical behaviors of wanderers
- Barriers includes bodies of water, fences, or ditches
- However, some barriers may not be recognized such as a ditch (could fall in), traffic (may walk into), or slopes
- The individual could settle into a spot that is not easily visible and will not call or respond to calls
- Individual could also have a destiny such as a prior residence, workplace, or other specific location (restaurant they also dine at, store)
- According to a VA study:
  - 94% of cases are within 1.5 miles of where they were last seen
  - 47% were found in a creek, drainage ditch, and/or caught in briars or bushes
  - 61% will become seriously injured or die within the first 24 hours if not found

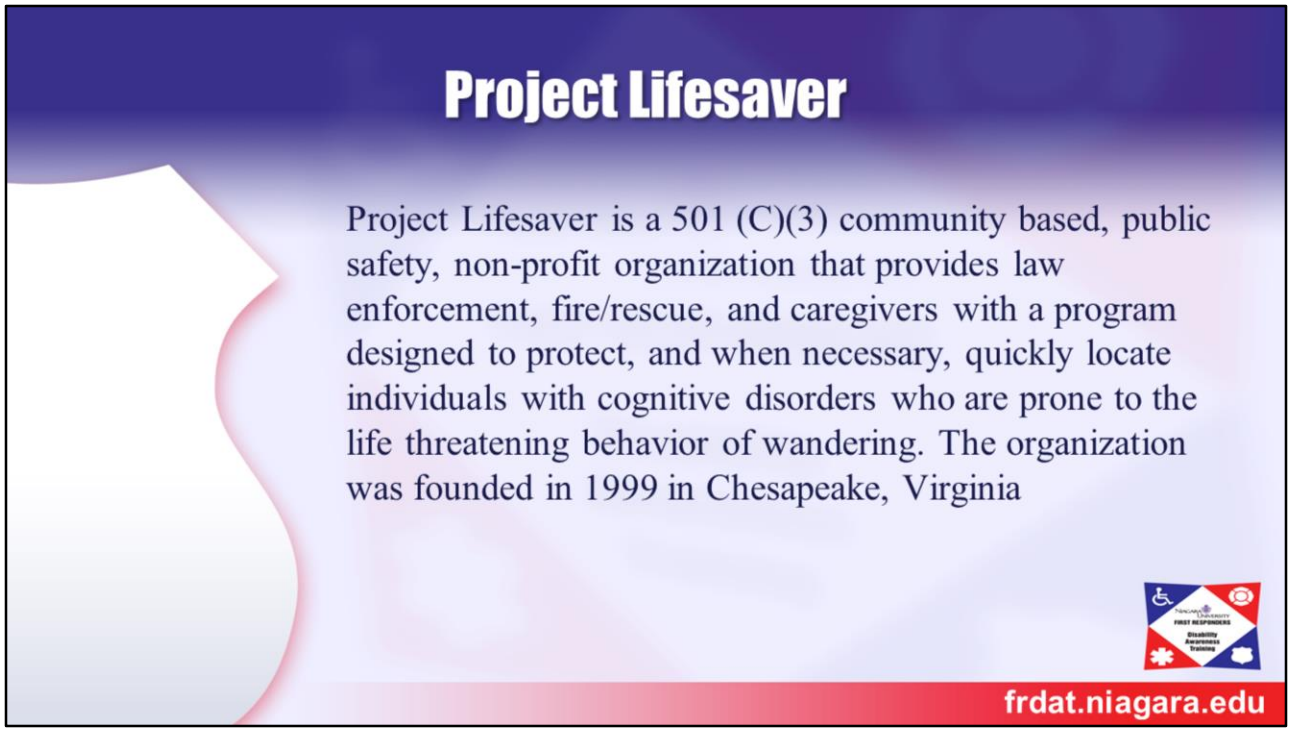
- 80% of those found after 72 hours died of hypothermia, drowning, or dehydration



- This shows how someone with Alzheimer's still has some recall.
- This also shows how officers who are aware of the disability can ensure a proper response

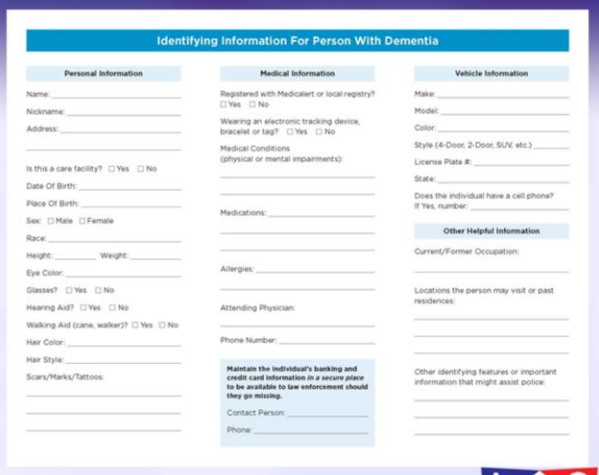


- With this service, critical medical information will be provided to emergency responders when needed.
- Bracelet has the number on top, person's name in the middle, and an ID number to verify them in the system
- Always look for a bracelet (or other forms of exposed ID).
- You may be the first call into Safe Return if you are first on the scene. Note the call may not come in as someone with dementia. It may because of their actions or behavior



- The Project Lifesaver Program is run at a municipality level by public safety agencies.
- When an agency decides to implement the program, Project Lifesaver International will equip them with the necessary technologies and provide training to those involved.
- The training includes the use of the equipment and the implementation of the strategic methods specifically designed for the program.

Alzheimer's Aware Adult ID kits



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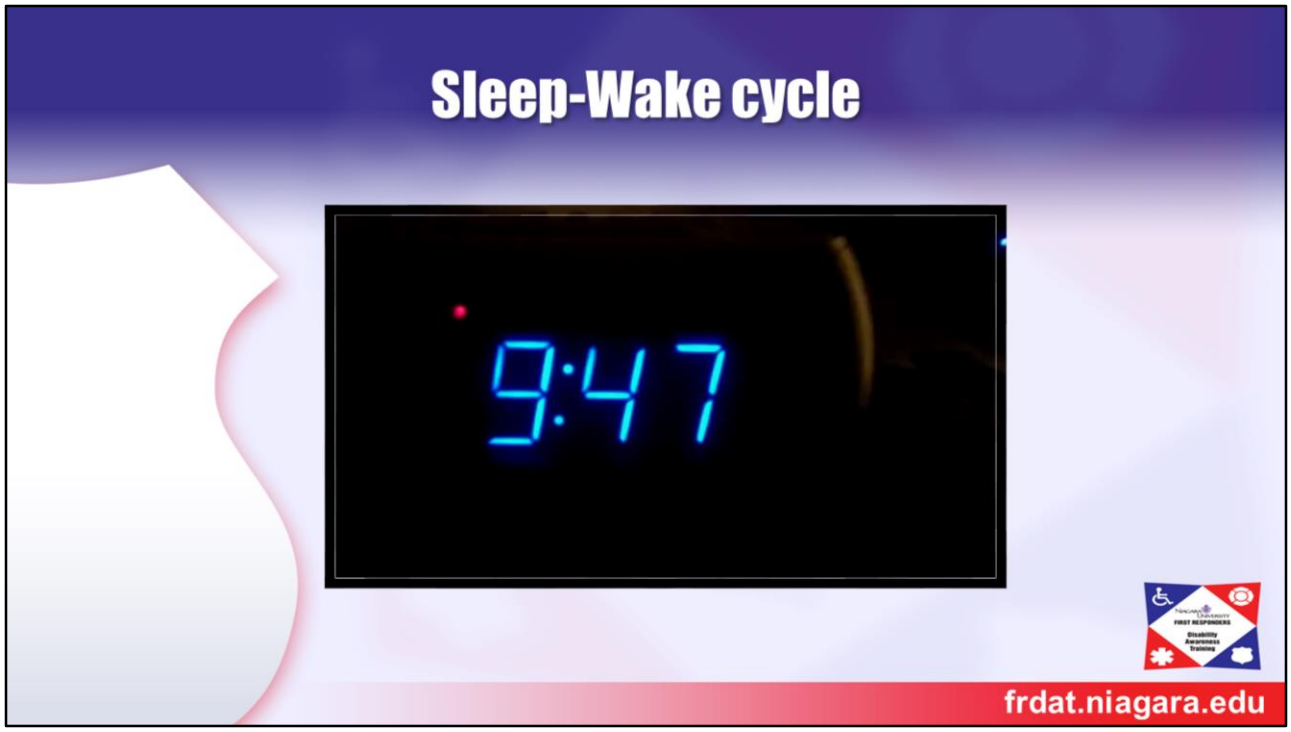
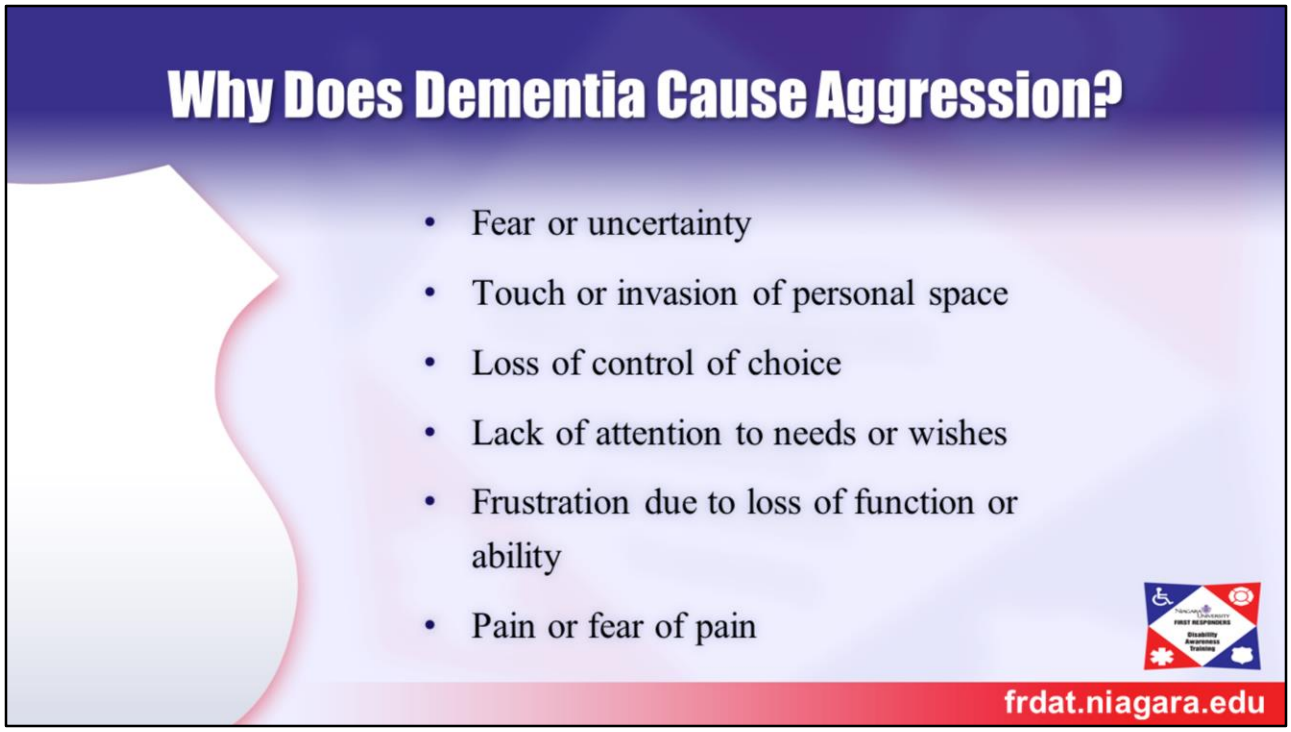
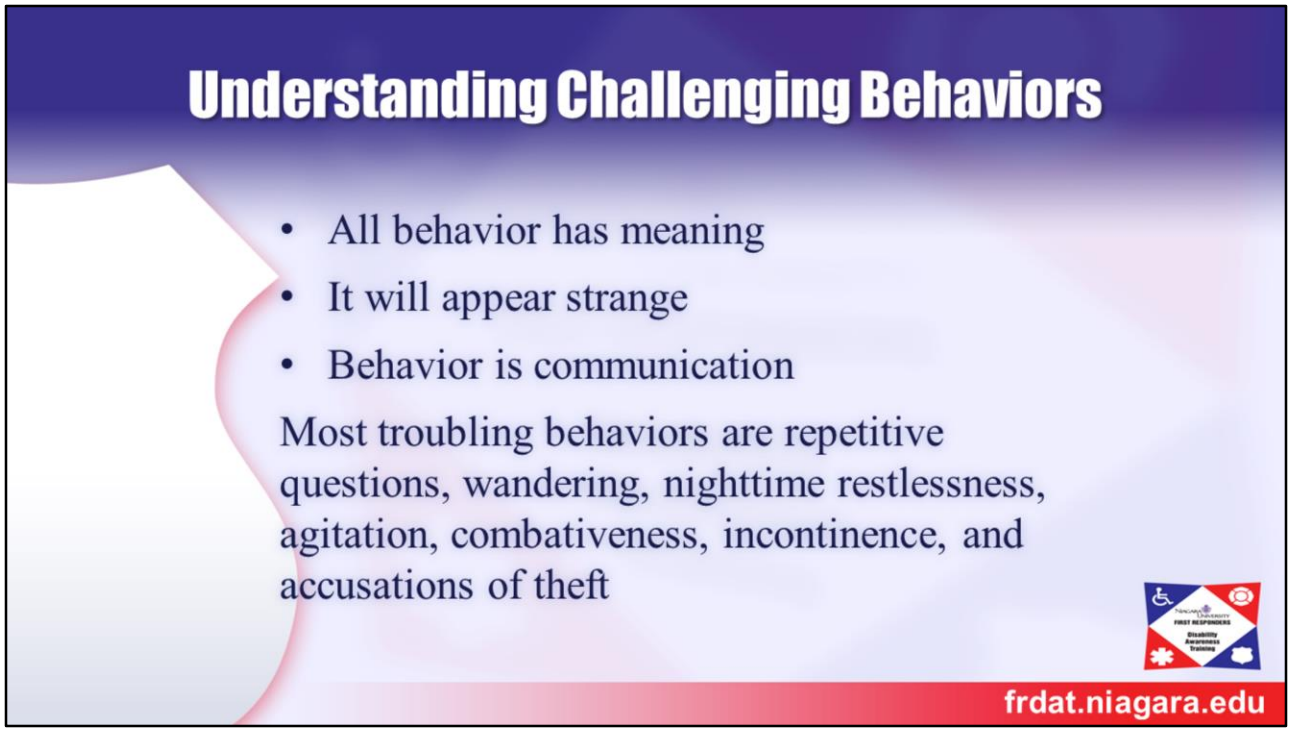


- Note the confusion, inability to answer questions and steady persistence.
- Recognize how challenging this would be for a caregiver



CLICK AND READ SLIDE

- Fear of you, not as an officer, but the person in 'that uniform with the lights on the car'.
- Remember, they very well may not recognize you as an officer.
- You are the person 'getting in their way'



- People with dementias often find it difficult to make sense of the world around them
- The inability to communicate is especially frustrating
- All behavior is a form of communication. If you went through the other Niagara University Law enforcement disability awareness training, you heard about this with autism and intellectual disability.

HEALTH PROBLEMS

- We can not rely on the person to tell us what is wrong
- Adverse drug reactions and medical problems can be the cause of the behavior
- Some health problems, if treated, may stop the behavior. Some examples are dehydration, fatigue, and constipation.

DIFFICULT TASKS

- An unfamiliar or complicated task may trigger a behavior reaction.
- Too many steps can make a task complicated
- This can as simple as getting dressed or making toast.

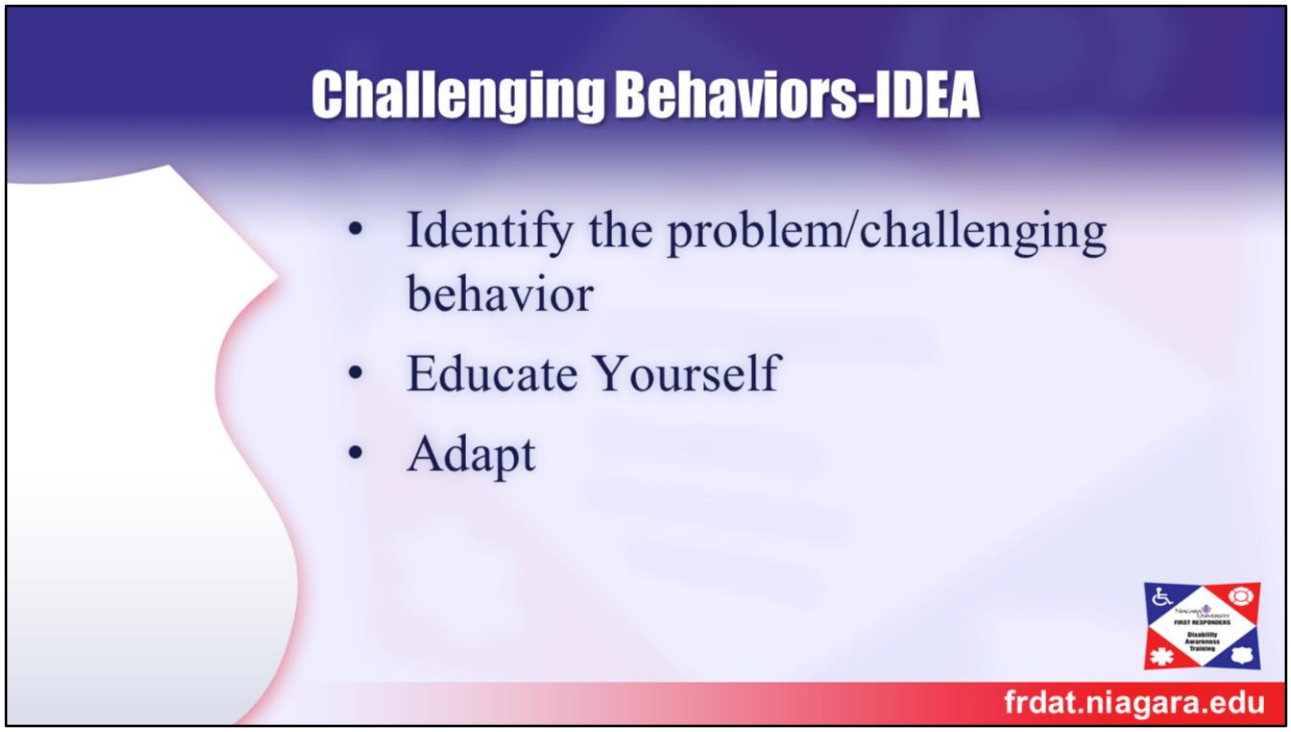
CONFUSING ENVIRONMENTS

- Surroundings which are crowded, unfamiliar, busy, or noisy can be very distressing

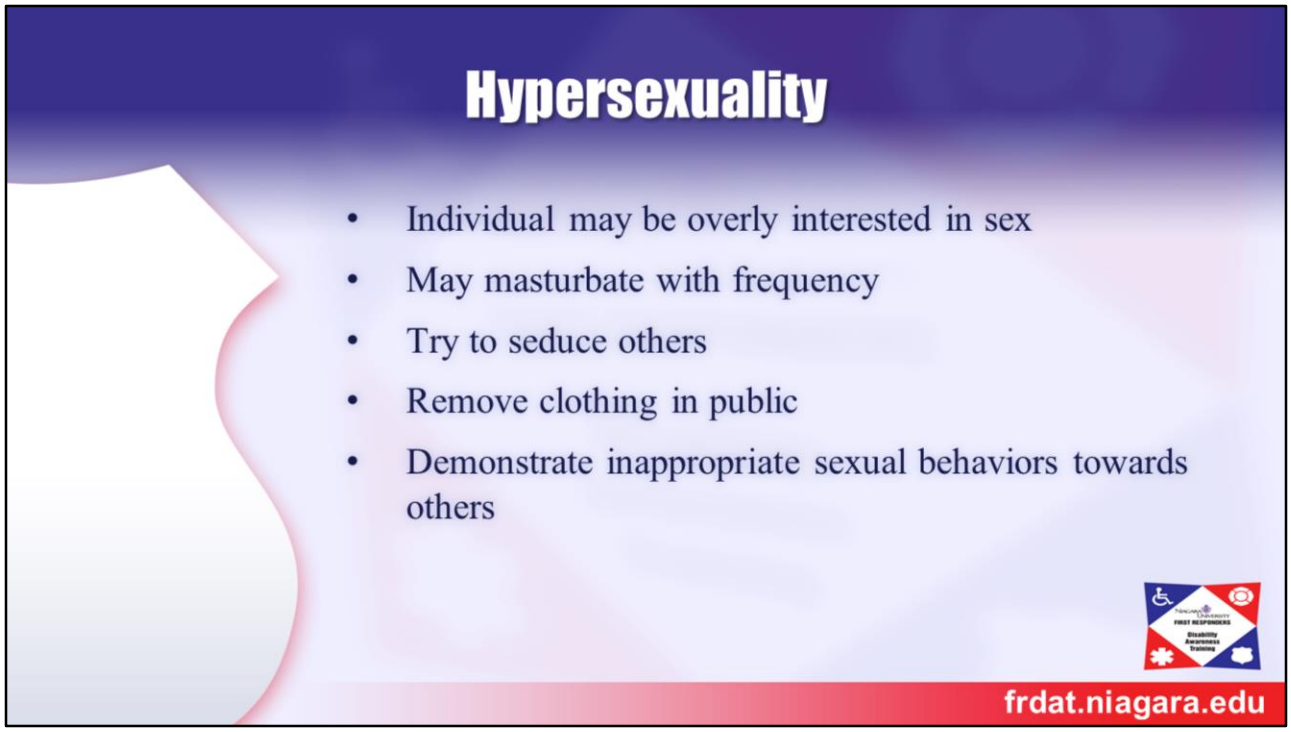
- Places need to be well lit, have plain floors (if possible) to include no black tiles or carpet.
- New places may also trigger behavior.

COMMUNICATION BREAKDOWN

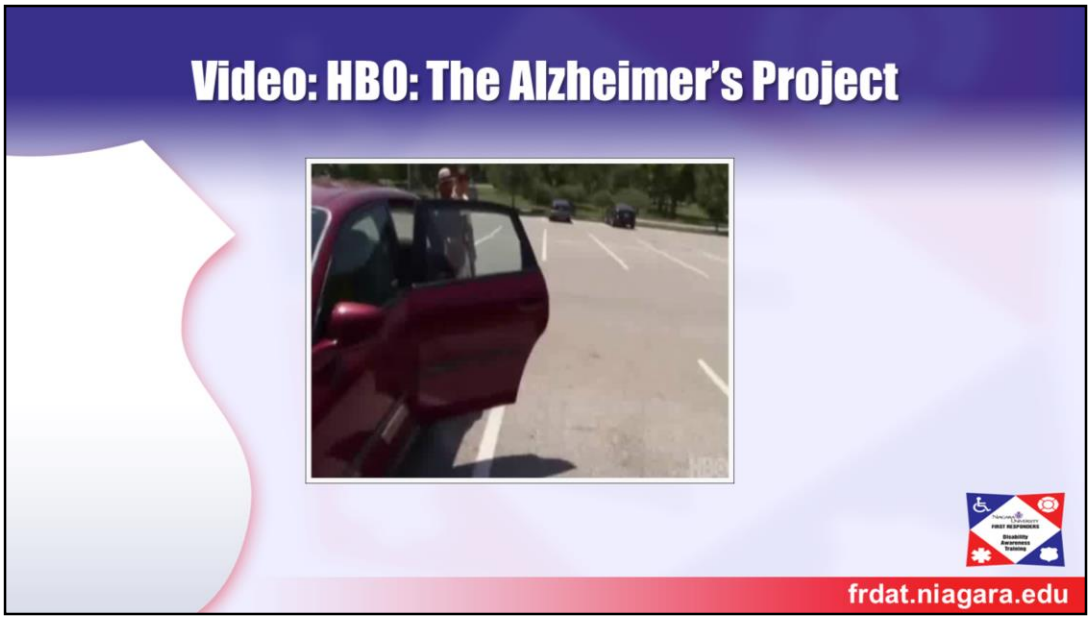
- People may have difficulty speaking and understanding what is said to them.
- To improve communication, go to a quiet location, speak slowly, and use cues such as pointing to say the bathroom if that is what is needed.
- Remember you set the tone
- Avoid arguing.



- IDEA! is a simple three step strategy to help you figure out *why* a challenging behavior is happening
- **Identify** why the behavior is challenging for you to deal with? Be specific
- **Educate Yourself** so you can understand the cause of the behavior
  - Health: Is the person taking a new medication, getting sick, or in pain?
  - Environment: Is it too noisy? Too hot? Are they in an unfamiliar place?
  - Task: Is it too hard, too many steps, or something new?
  - Communication: Is it hard for the person to speak or be understood?
- **Adapt;** Try different things. Pay attention to the person's feelings. Practice being calm, gentle, reassuring.

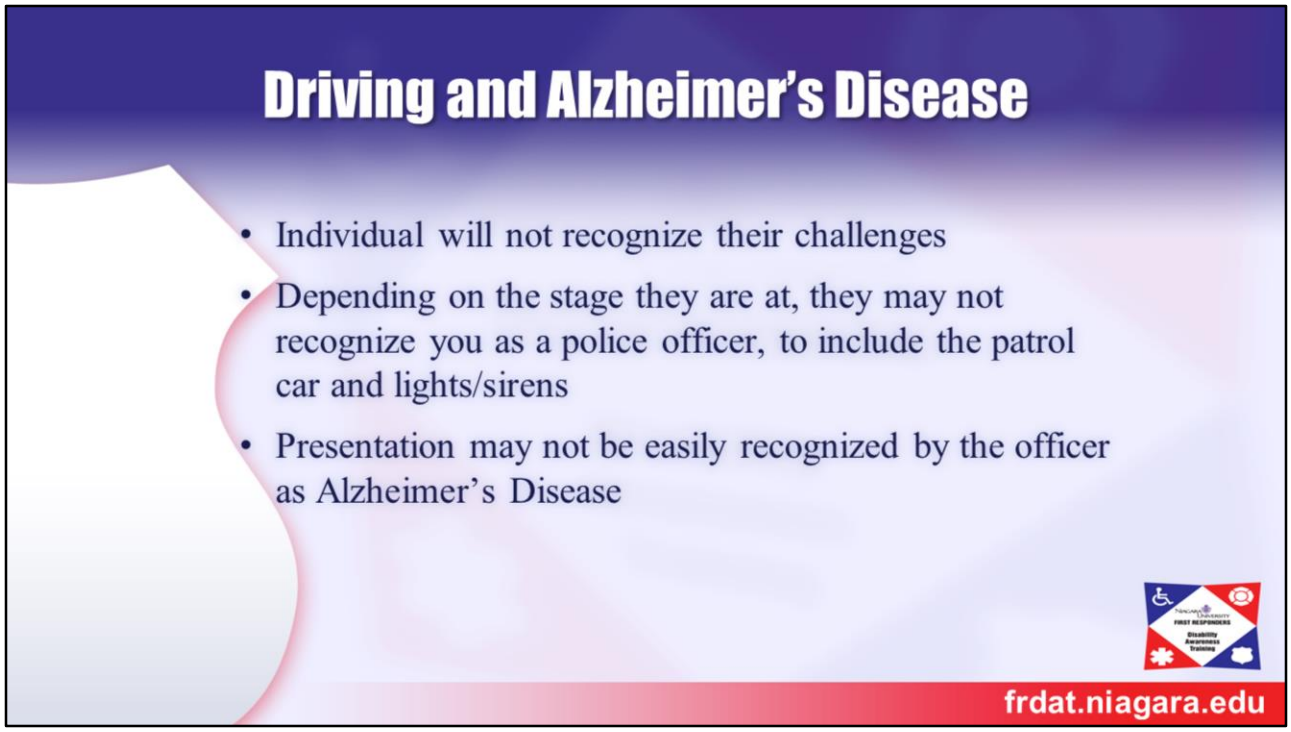


- These behaviors are symptoms of the disease and don't always mean the person wants to have sex
- As is obvious, some of these behaviors, especially in public, will most likely prompt a call for police presence.
- Don't try to reason with the person or explain that it is not appropriate behavior.
- Do not react with anger. Remember that this is part of the dementia and the person is not doing this on purpose.
- They are not sexual predators.



Video: **HBO: The Alzheimer's Project**

- Facilitate an open discussion with the class about what stage they think the driver is in.

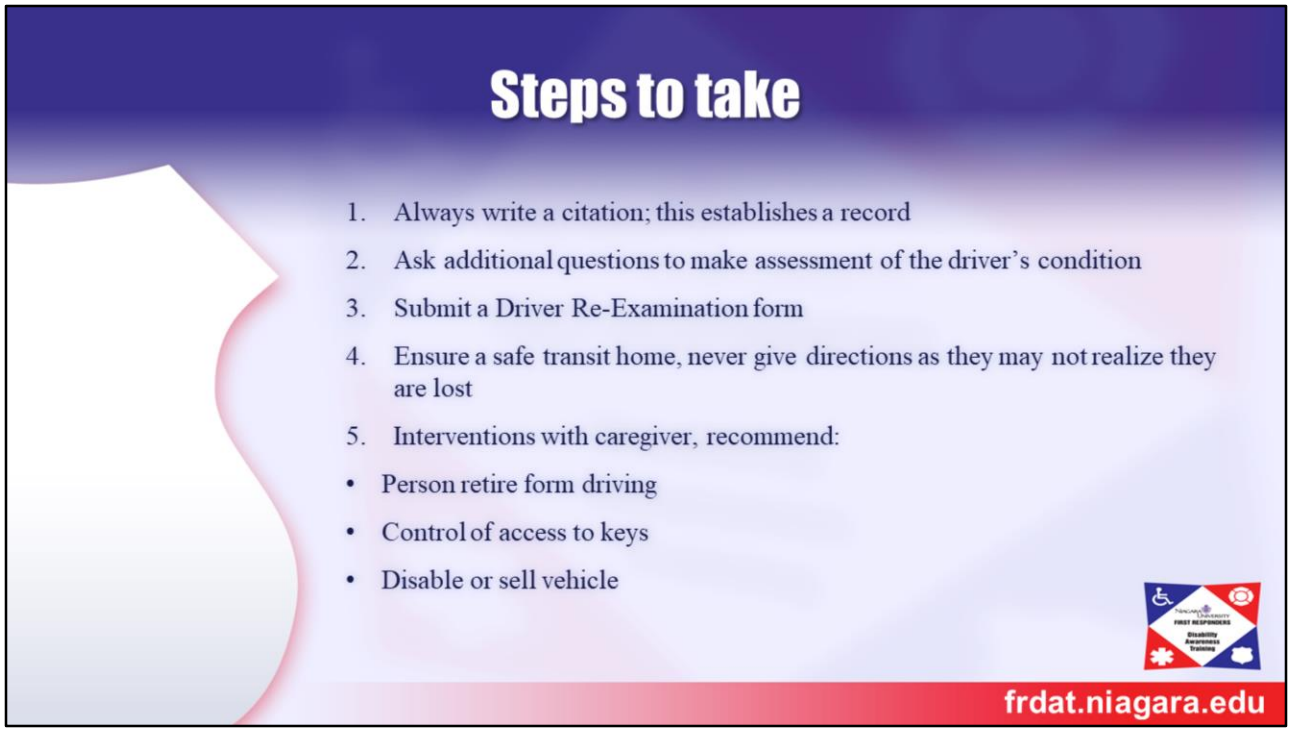


- Individuals with Alzheimer's Disease and some other dementias do not know they have it. Relative to driving, they will not recognize their poor or reckless driving.

- They may present to you as defiant, belligerent, a 'little confused' or as a typical aging senior. Recognition is pivotal when it comes to driving. We do not want someone to get back behind the wheel.

- When questioning, look for replies that do not make sense or are incomplete
- Someone forgetting where they live, where they are going, or where their son/daughter lives are telling signs.
- Be observant of any erratic driving that includes (very) slow speeds, stopping abruptly, or no indication they even intended to stop, or dangerous lane changes (no directional or squeezing into tight spaces)

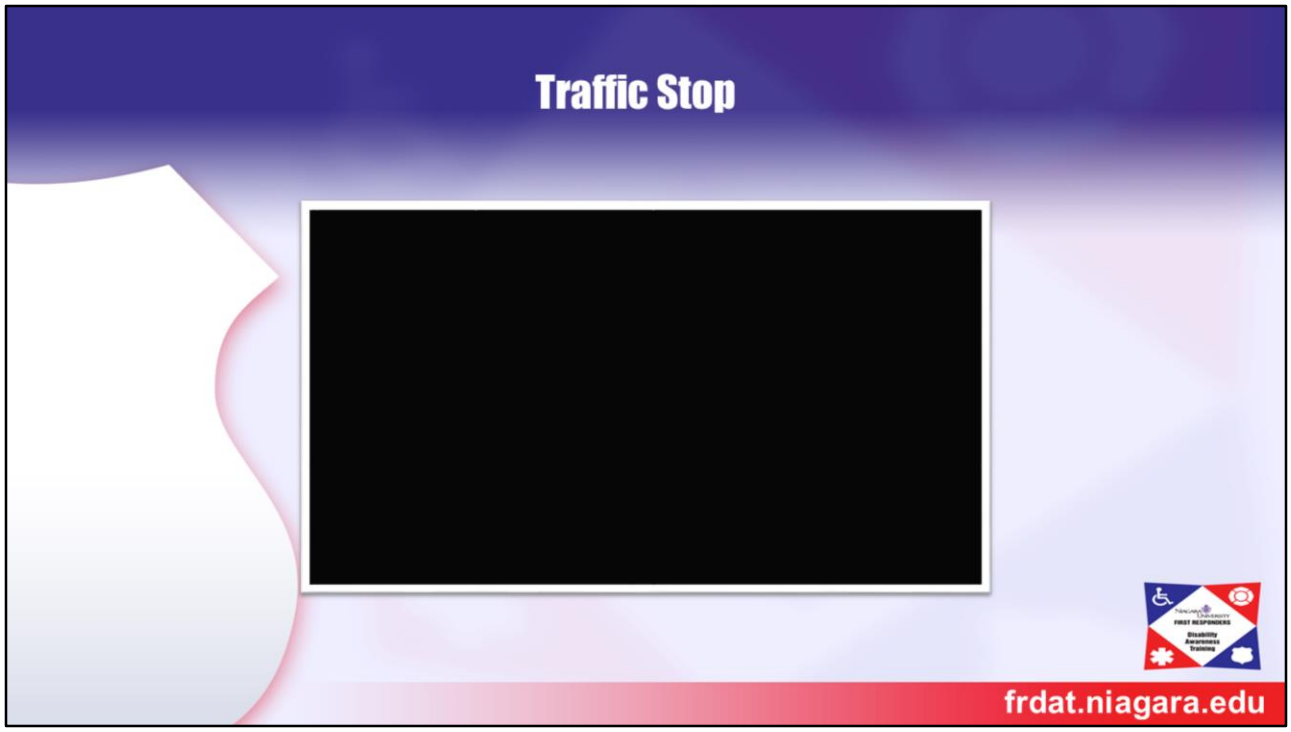
- When asked "Where are you going today?" can the person give an immediate response?
- Does the location they have identified make sense for this particular route of travel?



- The citation provides a trail. Do not let this slide out of sympathy.

- The caregiver very well may be aware of the decline of their family member/loved one, but a directive from a police officer reinforces the point that this is dangerous.

- That said, it may be easier said than done to stop the person from driving.



- Officer recognizes there is something different here, this is to commended.
- Gentleman is set in his course, needing to get to his sister. This will be common, overlooking the violation or any other wrongdoing.
- He did recognize the officer, to some degree. Many individuals may not recognize you even though you are in full uniform and driving a patrol car. This would be a clear indication you are not dealing with inebriation or defiance.

Responding to Dangerous Driving

- Identify yourself and explain why the person is being pulled over
- Do not argue with the person
- Talk to caregivers
- Refer to the DMV
- Issue a citation
- Do not let the person drive home

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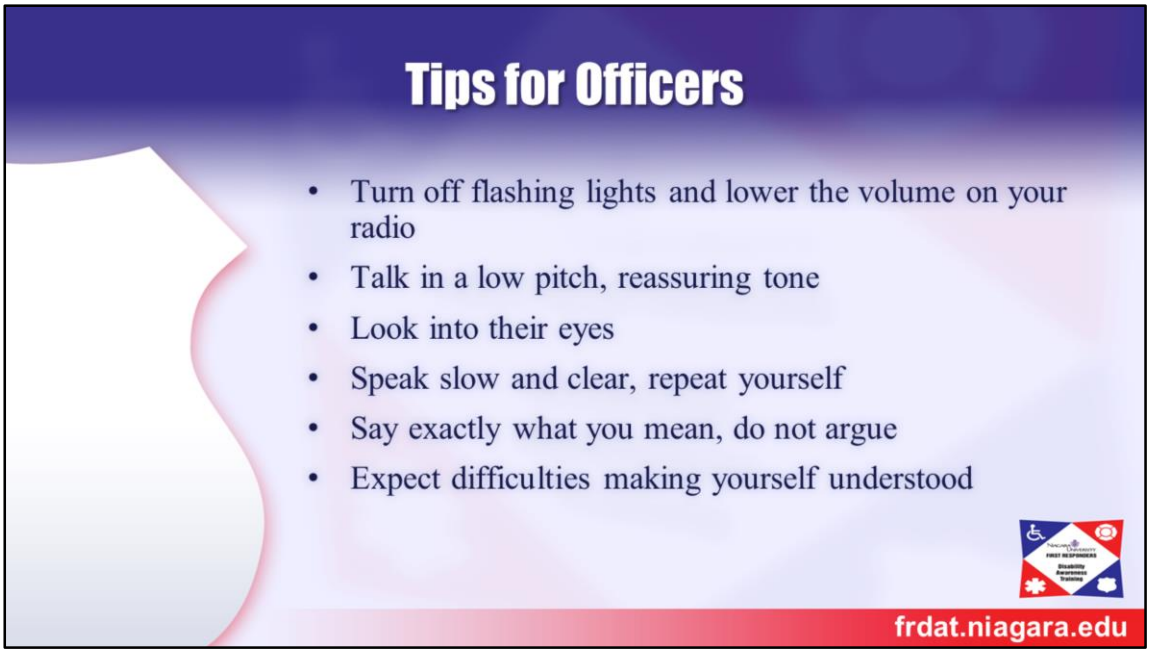
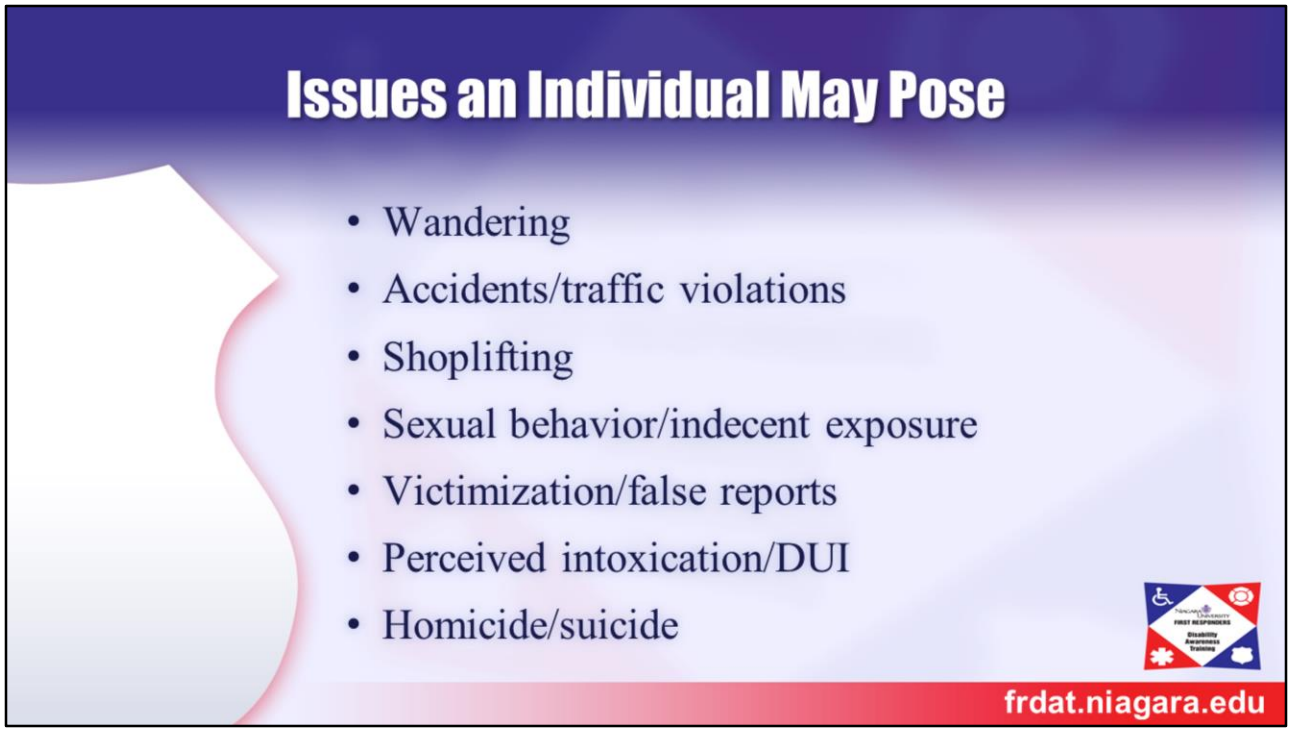


CLICK AND READ 6 BULLETS

- Look person in the eye, call by name, identify self, approach from front, use gentle touch if necessary.
- Use simple, adult words. ***Slow down*** when talking. Ask questions one at a time (no multiple questions in a sentence). Avoid using pronouns (he, she, they, etc.).
- Allow time for person to answer (may take time to "find" words). Repeat questions if necessary. Watch person's body language for clues.
- Try to change the subject if the person begins to argue with you. Ignore repetitive statements if they are not emotionally charged. Talk in positive terms (avoid the word *don't*). Ask for cooperation and help.
- Use gestures to explain what you want. Use events to measure time ("before or after lunch" is more reassuring than "in an hour"). Write notes if you are sure the person can read.



CLICK AND READ "WANDERING"

- Many individuals with Alzheimer's disease will wander if they are not watched over by a caregiver. They may not be dressed for the weather conditions and could be outside awhile if not found soon.
- 47% of individuals who wander in the Northeast and are missing for 24 hours are found dead, the highest ratio in the country (NYS DCJS Missing Persons).

CLICK AND READ "ACCIDENTS"

- Driving becomes a hazard and the incidence of accidents, traffic violations, as well as the possible perception that they are inebriated will challenge officers.
- Individuals in the moderate or severe range will not recognize you as a first responder, even though you are in full uniform and are driving a police car.

CLICK AND READ "SHOPLIFTING"

- They may be in a store and take an item without paying for it, unable to comprehend their actions as stealing or even forget they have the item.

CLICK AND READ "SEXUAL BEHAVIOR"

- Undressing in public may occur, not grasping the concept of exposure. An individual may also play with zippers and buttons. Bystanders may perceive this as public lewdness.

CLICK AND READ "VICTIMIZATION"

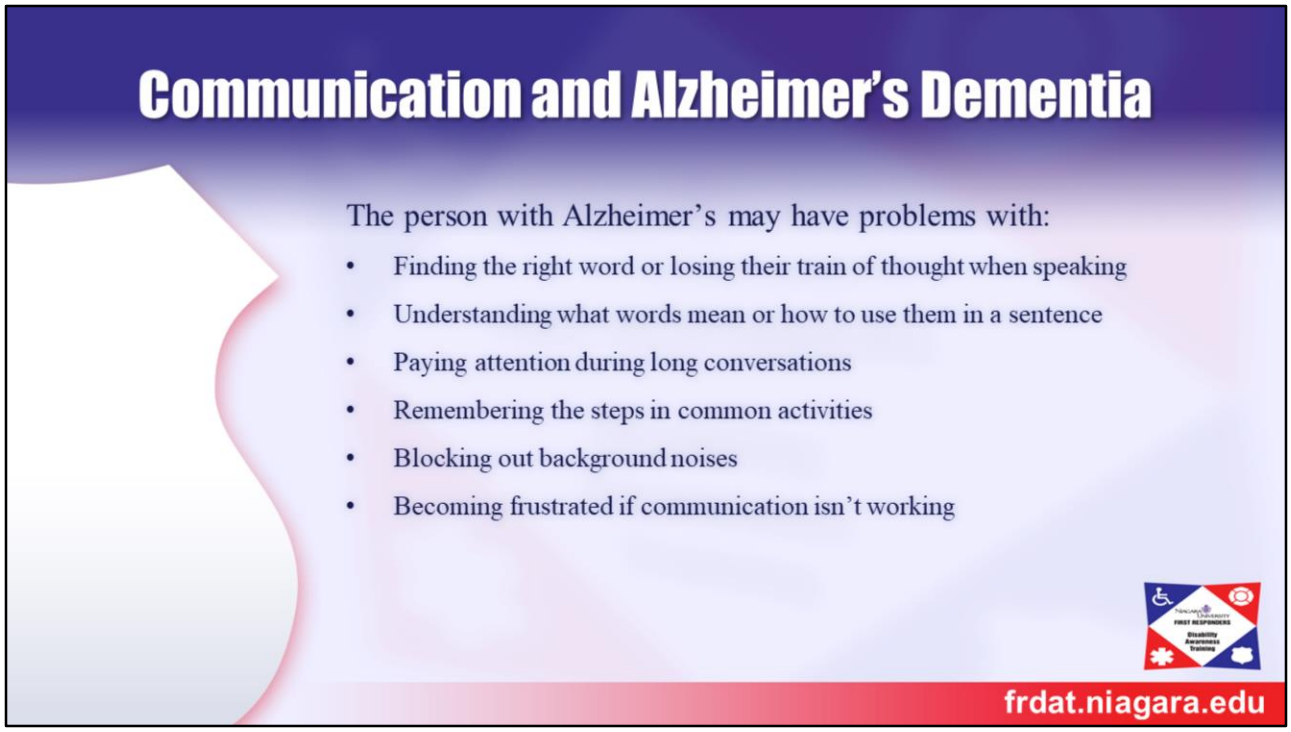
- Individuals can be easily manipulated by criminals who take advantage of their inability to grasp the situation at hand. Conversely, they may feel people are taking advantage of them when they are not and may falsely accuse.

CLICK AND READ "INTOXICATION"

- Individuals' actions or behavior can be perceived as public intoxication. This would include pulling someone over and the thought that they were drinking and driving.

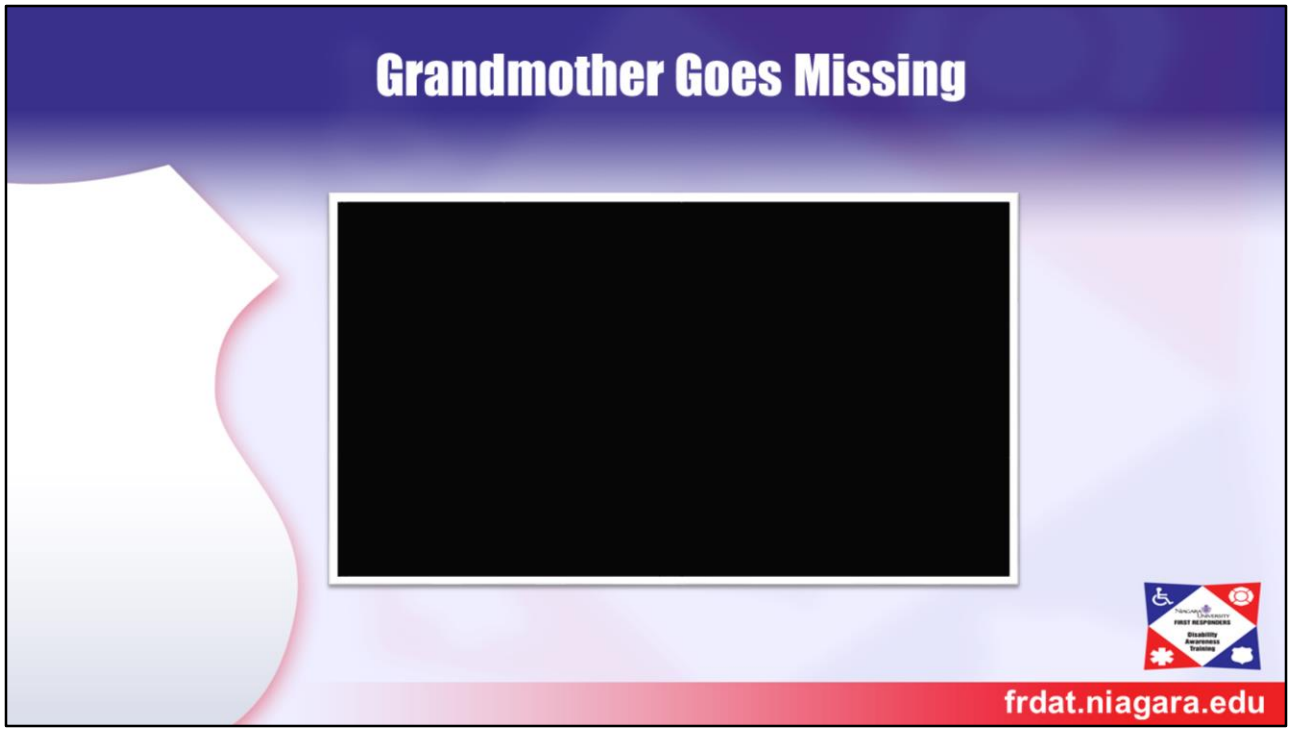
CLICK AND READ LAST BULLET

- Caregivers may not be able to deal with the challenges their loved one now poses. In a very real sense, they have lost them even though they are still alive. Some will decide that it is not worth the challenges and grief.

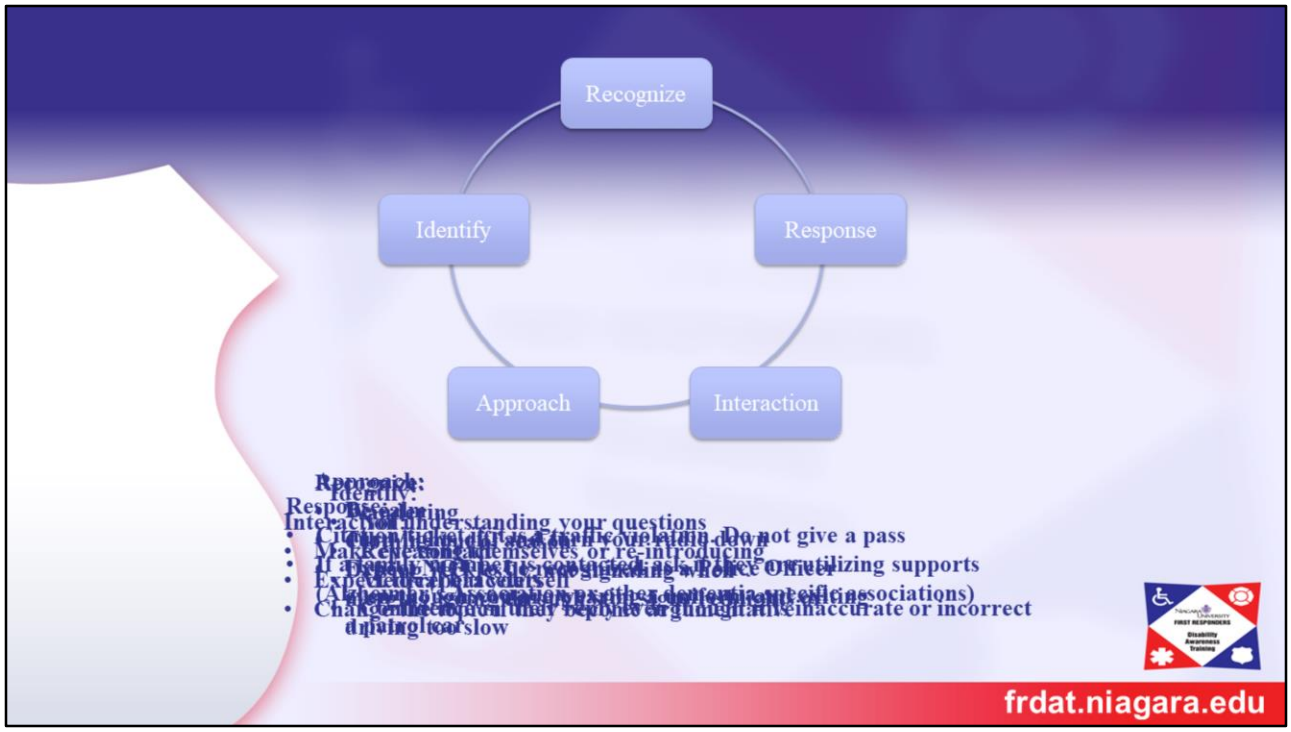


- You may feel impatient and wish they could just say what they want
- They may struggle to find words, or forget what they want to say
- They may no longer be able to use words at all

- Be patient with angry outbursts. Remember, it's the illness "talking."
- Let him or her male some decisions and stay involved.
- Repeat instructions and allow more time for a response.
- Try not to interrupt.
- Don't talk about the person as if he or she isn't there. This will only be more confusing.
- Don't talk to the person using "baby talk" or a "baby voice."



- This PD well prepared to address a person with dementia who is gone missing.
- Note the second check of the house.
- Good point to bring a neighbor or someone who knows the person so there is some recognition of a person. In this case, the grandmother seems unlikely to recognize law enforcement in uniform.



Recognize:

- Wandering
- Clothing out of season
- Driving recklessly; not signaling when merging, going through stop signs/red lights or driving too slow

Identify:

- Not understanding your questions
- Repeating themselves or re-introducing
- Medical bracelets
- Confidence in their reply even though it is inaccurate or incorrect

Approach:

- Be calm
- Turn lights off, and turn your radio down
- Expect NOT to be recognized as a Police Officer even though you are wearing a uniform and exiting a patrol car

Interaction:

- Make eye contact
- Expect to repeat yourself
- Change the topic if they become argumentative

Response:

- Citation/ticket if it is a traffic violation. Do not give a pass
- If a family member is contacted, ask if they are utilizing supports (Alzheimer's Association or other dementia specific associations)

Huntington's Disease

Objectives:

- Huntington's Disease Defined
- Signs and Symptoms of Huntington's Disease
- Behavior Symptoms
- Strategies for Law Enforcement
- Identifying challenges posed to law enforcement

Main points: HD can present in various ways to a Law Enforcement officer. Most characteristic present in a way that may result in public making calls to dispatch that someone is intoxicated or under the influence. Knowing these characteristics are vital to ensure an appropriate response. Suicide is three times more likely with someone with Huntington's disease.

Content:

- PowerPoint: 13 pages
- Videos:
    - Huntington Disease Video Clip
- Handouts:
    - Vital Information for Law Enforcement Interacting with Individuals wi th Huntington's Disease (HD)
    - Key Points for Incarceration/Confinement for Huntington's Disease

Resources:

- Huntington's Disease Society of America: Phone: 212-242-1968 Website:www.hdsa.org

Key Points

Please post in prominent place

Huntington's Disease Society of America

INCARCERATION/CONFINEMENT

Huntington's disease poses extra challenges for individuals who are detained or incarcerated. Safety concerns may warrant increased observation, separation from the general public, or confinement in the hospital wing of a correctional facility.

Physical/Motor concerns

- Balance problems/Falling
- Unsteady gait
- Uncontrolled gestures
- Falling/Vaulting out of bed
- Speech problems
- Choking danger/Swallowing problems
- Difficulty eating/Longer eating period needed

Psychological/Behavioral concerns

- Reduced impulse control
- Irritability/Combativeness
- Explosive outbursts
- Aggression/Fighting
- Sexual disinhibition, including public masturbation and inappropriate sexual advances towards others
- Depression/Apathy
- Obsessions/Compulsive behavior
- Extreme mood swings, paranoia and hallucinations (rare)

Cognitive concerns

- Memory problems – slowed processing/ Inability to learn new information
- Difficulty following multi-part directions
- Confusion/Distraction/Disorientation
- Need for more time to answer questions

Concerns around eating and nutrition

- A special diet may be required to prevent choking or pneumonia.
- Some people with HD may need to eat alone to prevent choking due to distractions.
- HD persons require more time to eat
- Consumption of food and water should be monitored to avoid dehydration and malnutrition.
- A person with HD burns calories at a faster rate. Incarcerated people with HD may need larger food portions.

Medications

- People with HD may be taking medications for their symptoms. It may be medically essential for them to continue taking these medications while incarcerated.
- Because of the need to continue taking medications, people with HD may be more safely confined in the hospital wing of a corrections facility.

Please contact HDSA for additional information and resources at 888-HDSA-506

Huntington's Disease Society of America

Defining Characteristics of HD

- Psychiatric/behavioral disorder
- Movement disorder symptoms
- Cognitive disorder causing changing mental function
- Adult-onset in approximately 95% of all cases
- Genetically inherited
- Progressive and degenerative over many years
- Purely neurologic disorder (spares other organs)
- Fatal

The most important things to keep in mind about HD are:

1. HD affects three aspects of normal function:

a. The psychiatric symptoms of HD affect an individual's behavior

b. The motor symptoms of HD affect an individual's movement.

c. The cognitive symptoms of HD affect an individual's thinking.

2. HD gets steadily worse and is therefore known as a progressive disorder. The challenges that people with HD and their families face change over time.

3. The three aspects of HD affect each other. For example, someone with HD may be frustrated due to an inability to answer a question or express a need, and this can precipitate an emotional outburst or increase the uncontrolled movements.

4. It is vital to be aware of the impact of unawareness, a common symptom of HD, which causes the affected individual to deny, minimize, or truly be unaware of, the extent of his or her symptoms. Unawareness is due to damage to their brain. As a result:

a. People with HD often will not have an "Aha!" moment where they suddenly understand what is happening.

b. It is necessary to consult the caregiver for supporting information whenever possible.

5. Huntington's disease poses extra challenges for incarcerated individuals.

Questions to Ask the Caregiver

The caregiver of the person with HD can be a valuable resource, and may be able to provide information about their loved one's symptoms and behavior. Because unawareness is a symptom of HD, getting supporting information from caregivers is can be essential to defusing a confrontation and avoiding detention for any period of time.

General Information

- Does this individual have an HD Profile form?

Orientation/Safety

- Does the individual with HD understand what is going on? Is he/she oriented to person, place and time?
- Is the caregiver in fear or danger?
- Is the person with HD dangerous or suicidal?
- Does the person with HD have any problems eating and swallowing?

Behavior

- Is there anyone else besides the caregiver that police can call to calm down the person with HD?
- What are some specific or concrete steps that work to calm the person with HD down, if any?
- Is the presenting behavior normal for the individual? What is the normal baseline in regards to behavior for the individual?
- Have their behavioral problems caused any criminal charges in the past?

Medications

- Is the person with HD taking medications?
  - Do you have a written list of your loved one's medications and dosage?
  - Is the individual on antipsychotic medications?

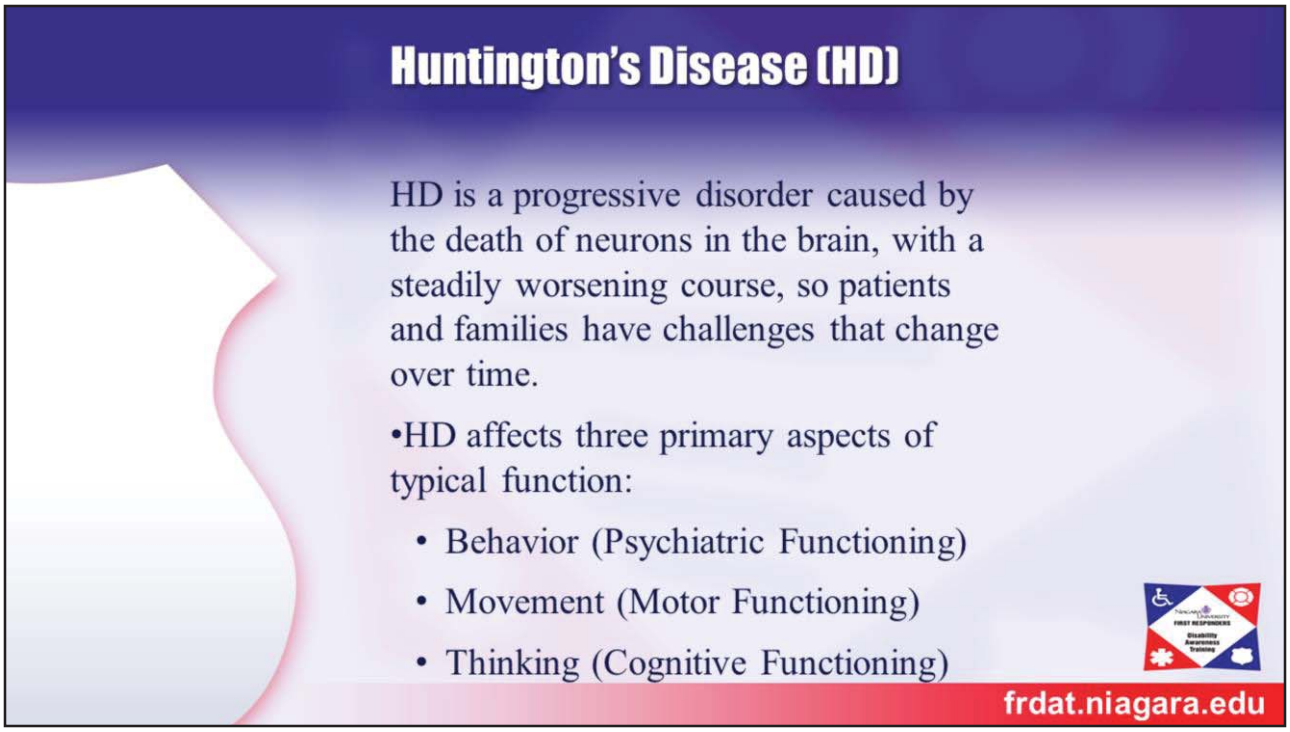
Guardianship/Power of Attorney

- Is the individual with HD under guardianship?

Please contact HDSA for additional information and resources at 888-HDSA-506

HANDOUTS:

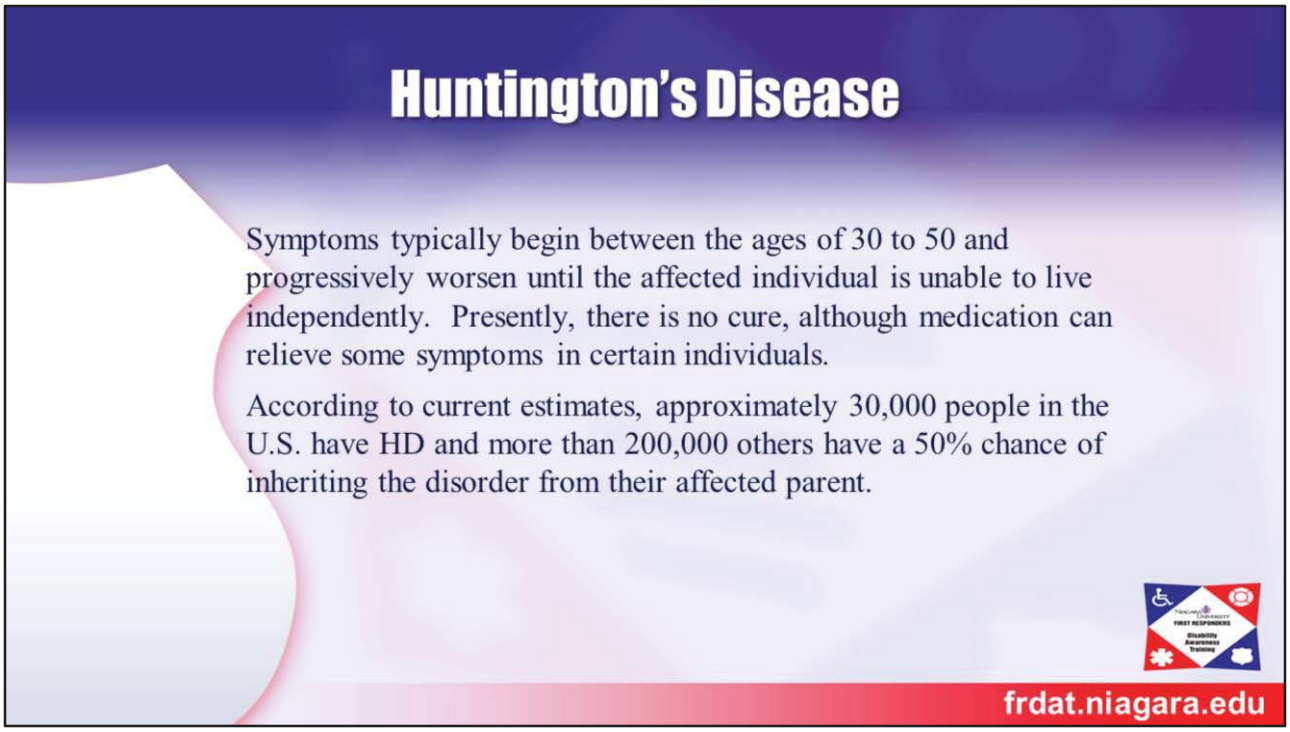
- Vital Information for Law Enforcement Interacting with Individuals with Huntington's Disease (HD)
- Key Points for Incarceration/Confinement for Huntington's Disease



CLICK AND READ FIRST BULLET

- These changes can be confusing and debilitating for all family and friends, not just the individual

CLICK AND READ SECOND BULLET


Huntington's Disease
Symptoms typically begin between the ages of 30 to 50 and progressively worsen until the affected individual is unable to live independently. Presently, there is no cure, although medication can relieve some symptoms in certain individuals.
According to current estimates, approximately 30,000 people in the U.S. have HD and more than 200,000 others have a 50% chance of inheriting the disorder from their affected parent.
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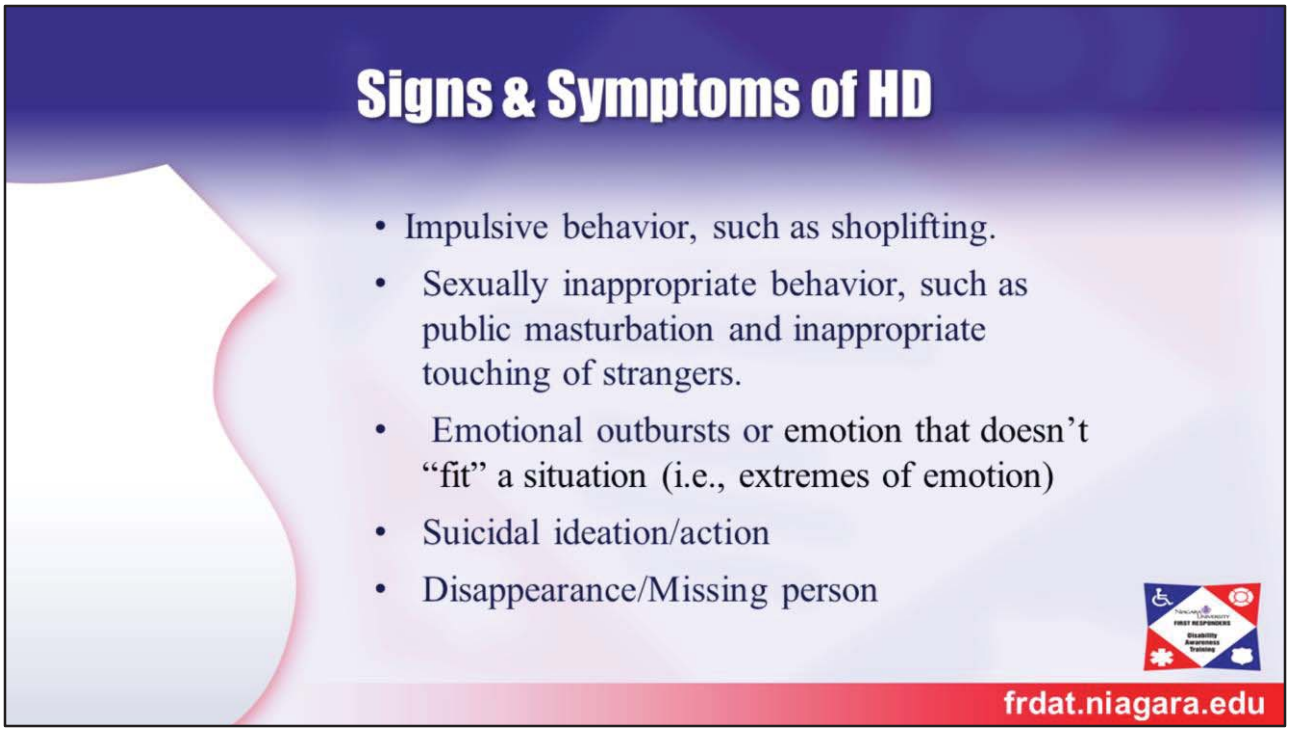

CLICK AND READ 5 BULLETS

- Most of the behavior listed on this slide/talking points could easily involve officers called to the scene.
- Impulsivity can lead to illegal behavior, such as shoplifting. Parent or other adult should try to explain why their relative shoplifted an item & return it to the store, or pay for it.
- Some problems w/LE happen because of misinformation about HD & officers not knowing about symptoms; some are due to behavioral aspects of HD
- Few to no filters; whatever s/he wants, is likely to break the law or say & do things considered socially inappropriate. An inability to delay gratification may lead to inappropriate action or language
    - May take off clothes in public
    - May masturbate in public
    - May touch others in a socially/sexually inappropriate

manner
- People with HD may stalk another person
- If behavior is ignored, it may escalate to sex abuse or assault.
- Someone who fits this description shouldn't be left alone with children.

➢ Because of brain damage removing filters individuals with HD are at risk of arrest as sex offenders. Conversely, may lead to sexual abuse by a partner or stranger.

➢ Medication can be helpful in controlling physical symptoms as well as irritability, frustration, depression, and to some *small* extent, impulsivity

CLICK ON EACH BULLET AND GO THROUGH EACH SYMPTOM

- The following could easily lead to a suspicion of drunkenness, which is a class 4 misdemeanor:
- Staggering gait.
- Jerking or abrupt movements of the face, trunk or limbs.
- Slurred speech.
- Speech too loud or soft, fast or slow.
- Driving erratically or too slow (this may be caused by physical *or* cognitive difficulties)
  - **Breathalyzer** can help clear individual, but refusal may lead to arrest
  - On the other hand, person might actually be drunk…


Behavior Symptoms
• Irritability or combativeness
• Impulsive behavior, such as shoplifting
• Sexually inappropriate behavior, such as public masturbation and inappropriate touching of strangers.
• Explosive temper or over emotional
• Outbursts
• Driving erratically or too slow
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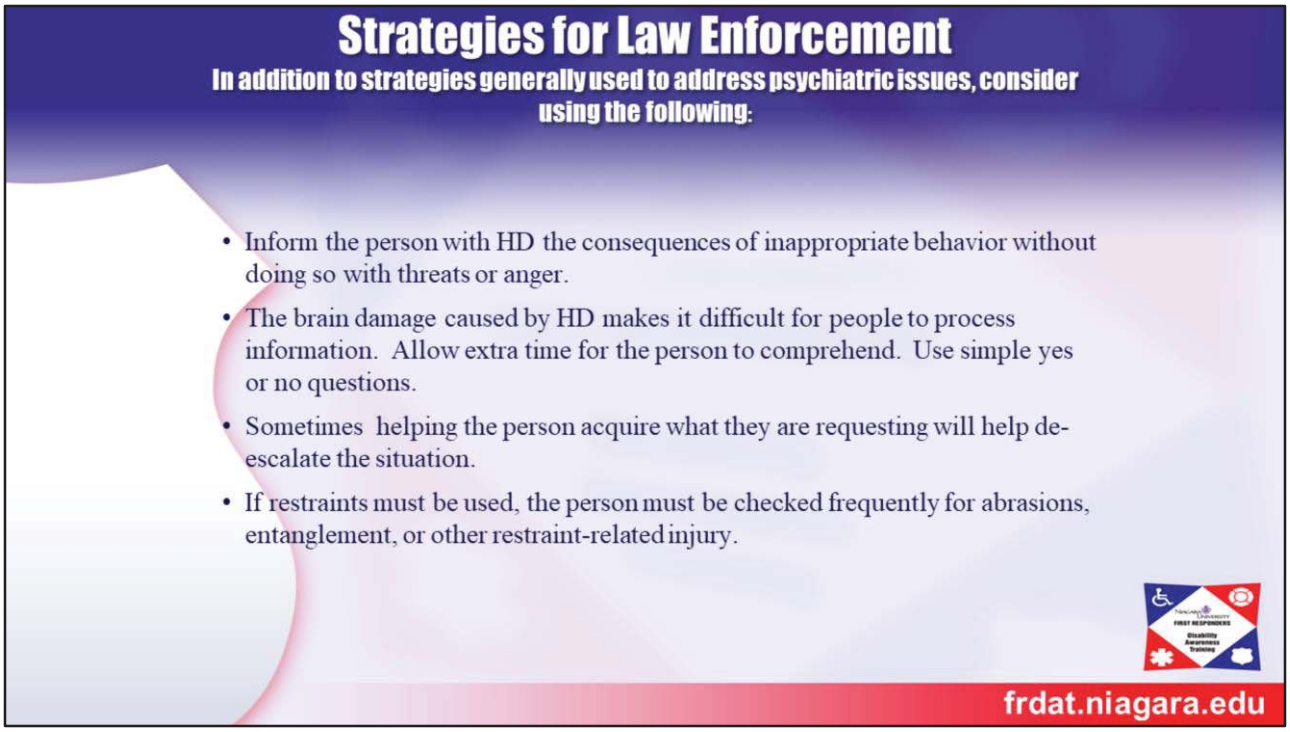
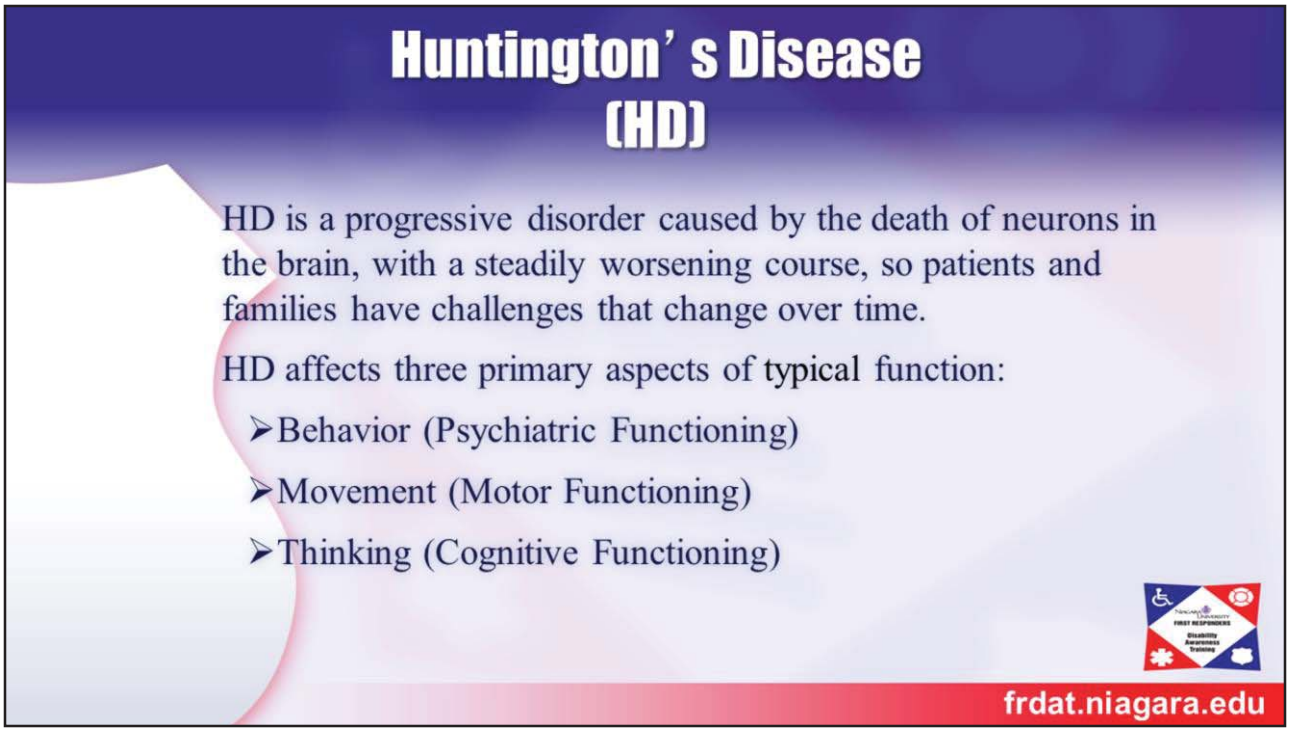
- Suicide is three times higher in people with HD than in the general population due to a combination of depression and lack of inhibition, both of which are symptoms of HD.
- Any expression of suicidality should be taken seriously with appropriate interventions.
- People with HD should be assessed for suicide risk.
- If detained, consider suicide watch for the incarcerated individuals with HD



CLICK EACH BULLET AND READ EACH SENTENCE

PLAY VIDEO:

- Discuss what is shown in the video in comparison with the past slides



CLICK AND READ FIRST BULLET

- These changes can be confusing and debilitating for all family and friends, not just the individual

CLICK AND READ SECOND BULLET

CLICK AND READ FIRST SUB BULLET

- Outbursts
- Irritability or combativeness
- Explosive temper
- Obsessive-compulsive behavior

CLICK AND READ SECOND SUB BULLET

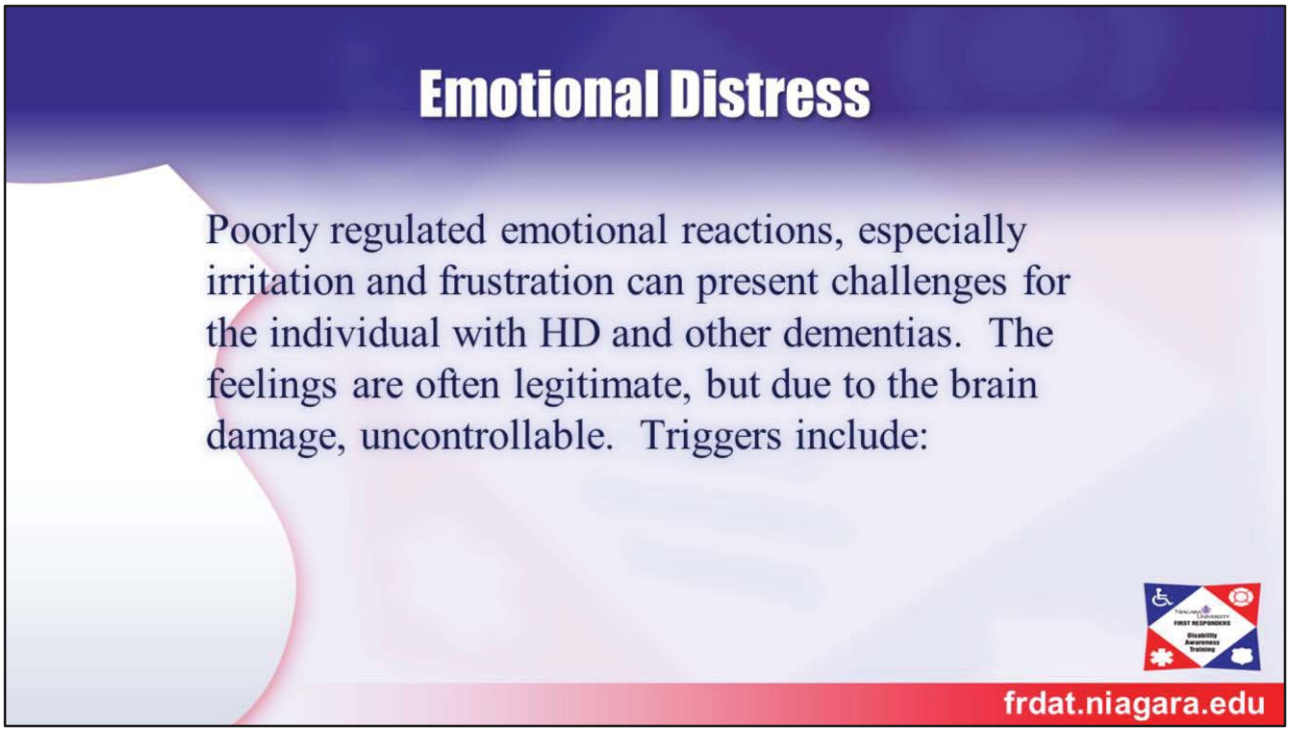
- The following could easily lead to a suspicion of drunkenness, which is a class 4 misdemeanor:
- Staggering gait.
- Jerking or abrupt movements of the face, trunk or limbs.
- Slurred speech.
- Speech too loud or soft, fast or slow.

- Driving erratically or too slow (this may be caused by physical *or* cognitive difficulties)
  - **Breathalyzer** can help clear individual, but refusal may lead to arrest
  - On the other hand, person might actually be drunk…

CLICK AND READ THIRD SUB BULLET

- Inability to answer questions quickly.
- Disorientation or lack of attention.

- Suicide is three times higher in people with HD than in the general population due to a combination of depression and lack of inhibition, both of which are symptoms of HD.
- Any expression of suicidality should be taken seriously with appropriate interventions.
- People with HD should be assessed for suicide risk.
- If detained, consider suicide watch for the incarcerated individuals with HD

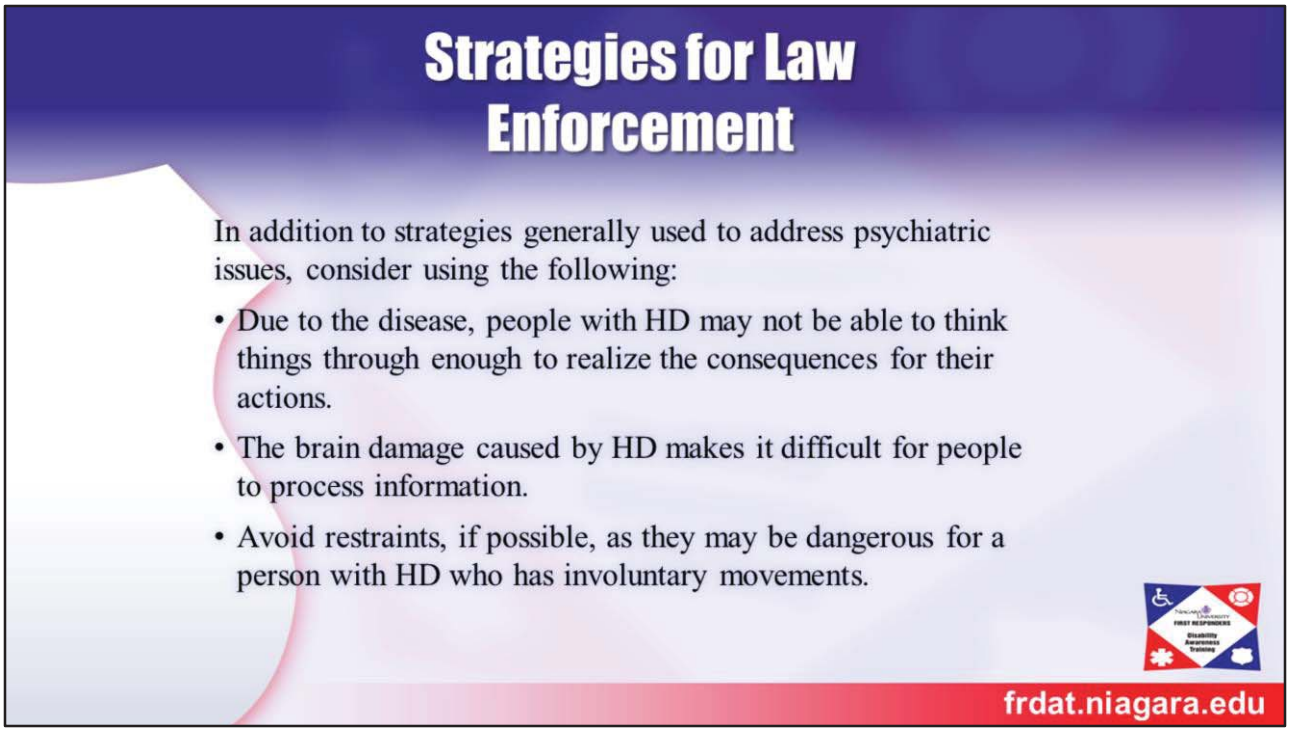


CLICK AND READ SLIDE

- Hunger
- Pain
- Inability to communicate
- Changes in routine
- Loss of ability to perform certain tasks
- HD causes changes in the brain that often make it difficult for a person with HD to see another's point of view.
- As a result, the individual may become easily frustrated or irritated if his or her views or ideas are challenged.
- A person with HD can rapidly escalate into severe anger; however, he or she can also calm down very quickly.

- People with HD are often prone to anxiety as well, this may lead to:
- Nervousness

- Restlessness
- Fidgeting
- Shallow breathing
- Sweating
- Fear
- Panic
- Rapid heart-rate
- Repetitive thoughts about bothersome topics



CLICK AND READ FIRST AND SECOND BULLETS

- Inform the person with HD the consequences of inappropriate behavior without threats or anger

CLICK AND READ THIRD BULLET

- Allow extra time for the person to understand. Use simple yes or no questions. This can help stop a person with HD from getting frustrated and reacting aggressively
- Keep the person calm, as stress can sometimes make a person's movement disorder worse
- Ask the person to take a breath, slow down, and repeat what they said
- Do not lie to the person about the severity of his or her situation. They are likely to know their behavior was inappropriate, but in the moment, they acted out of fear or impulsivity.
- Sometimes helping the person acquire what they are

requesting will help de-escalate the situation

CLICK AND READ FOURTH BULLET

If the person with HD is detained:

- If restraints must be used, the person *must* be checked frequently for abrasions, entanglement, or other restraint-related injury
- Be alert for choking, especially when the person is eating or drinking. (If the person is with a caregiver, ask about any problems eating and swallowing)
- A person with HD burns calories at a faster rate. Incarcerated people with HD may need larger food portions.
- Those in long-term incarceration should be weighed monthly, and weight loss reported to medical staff.

Closure

Objectives:

- Recommended Steps for Law Enforcement
- Virginia Specific Supports
- Referencing NU FRDAT for resources and information

Main points: Implementing the recommended steps mentioned in this section, will provide your agency with a seamless approach in dealing with individuals with Alzheimer's and other dementias. Knowing the available resources in your area is essential in knowing where to get consistent information.

Content:

- PowerPoint: 9 pages
- Videos:
    - None

Handouts:

- Alzheimer's Association of Virginia Resources

Resources:

- Virginia Department for Aging and Rehabilitative Services: Phone: 800-552-5019: Website: https://vadars.org/
- Alzheimer's Association: Phone: 1-800-272-3900: Website: www.alz.org

Alzheimer's Association of Virginia Resources

ALZHEIMER'S ASSOCIATION OF VIRGINIA'S PROGRAMS AND SERVICES

WHAT WE DO...

Alzheimer's Association of Virginia provides local, community based programs and services in many languages to help people with dementia, as well as their families, and caregivers, including:

24/7 HELPLINE

Alzheimer's Association of Virginia 24/7 Helpline 844.HELP.ALZ (800-272-3900) offers information, emotional support, and referrals for people with memory loss, caregivers, professionals, and general community members. The Helpline is staffed around-the-clock by professionals who understand the disease and its impact, and offers assistance in 170 languages.

CARE COUNSELING

Confidential Care Counseling and support helps families and caregivers of Alzheimer's disease with care planning, education and coping techniques. Individual and ongoing sessions, in person or by telephone, are available.

SUPPORT GROUPS

Alzheimer's Association of Virginia's support groups are open gatherings of people with common needs and interests who come together to share their experiences in an effort to better cope with and manage the challenges of dementia in a safe environment, and are held at various times and locations.

EARLY STAGE PROGRAMS

Information, education, family consultation, and support groups are available for those with memory concerns or who have been diagnosed in the early stages of the disease and their care partners. Alzheimer's Association of Virginia offers educational programs and support groups for people in the early stage of the disease, as well as their care partners.

ACTIVITY PROGRAMS

Several activity programs are offered for persons living in the mid-stages of dementia, and their caregivers. Participants enjoy cognitively stimulating activities, mingling, light refreshments, and interactive presentations on music, art, yoga, and much more.

MEMORIES IN THE MAKING

This unique fine arts program that offers a creative and non-verbal way of communicating and capturing precious moments through art. Small group classes are held throughout the community at various sites and in different settings.

MedicAlert+Safe Return

MedicAlert + Safe Return is a 24-hour, nationwide emergency response service for individuals with Alzheimer's disease or other dementias who wander and get lost, or have a medical emergency. An identification product provides emergency medical information and assists in the event of a wandering incident.

EDUCATION

Community outreach and education is offered throughout the Commonwealth.

PROFESSIONAL TRAINING

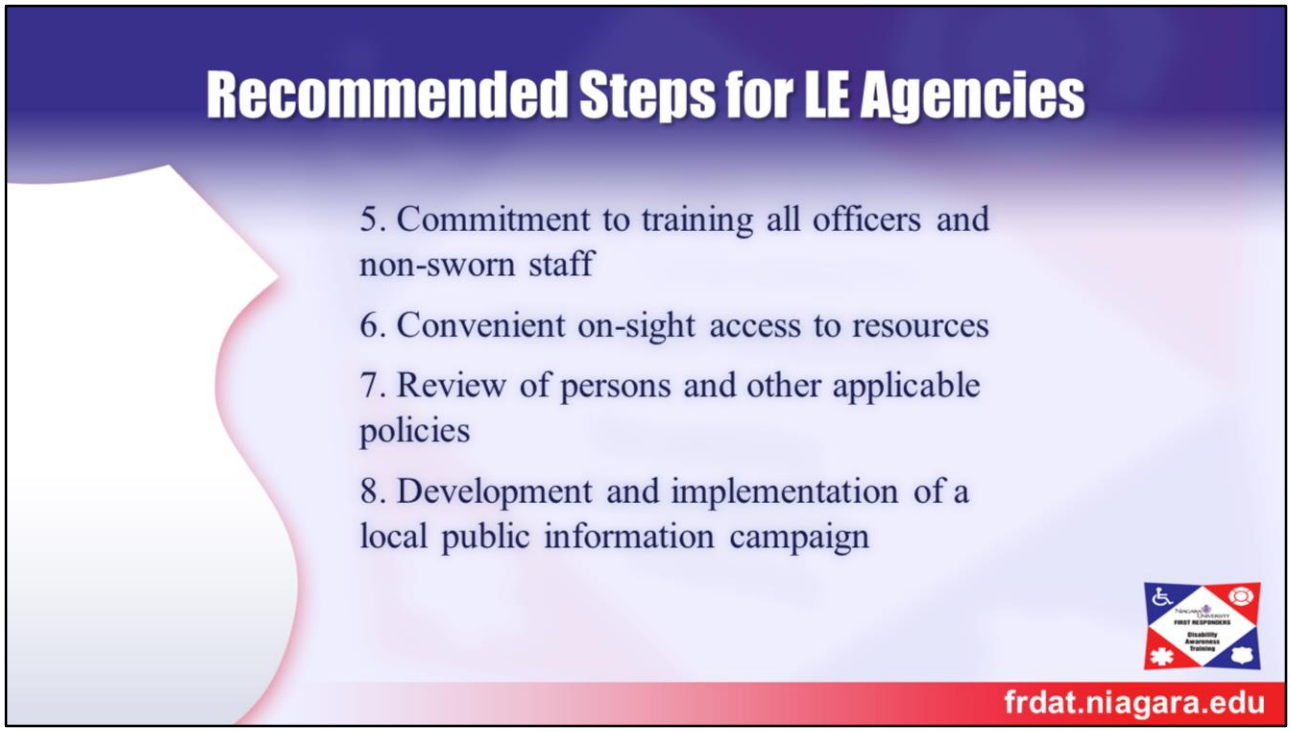
Alzheimer's Association of Virginia provides on-site and web-based trainings to professionals. Trainings can be customized to meet the specific needs of the training participants. Continuing education contact hours may be available.

Handouts:

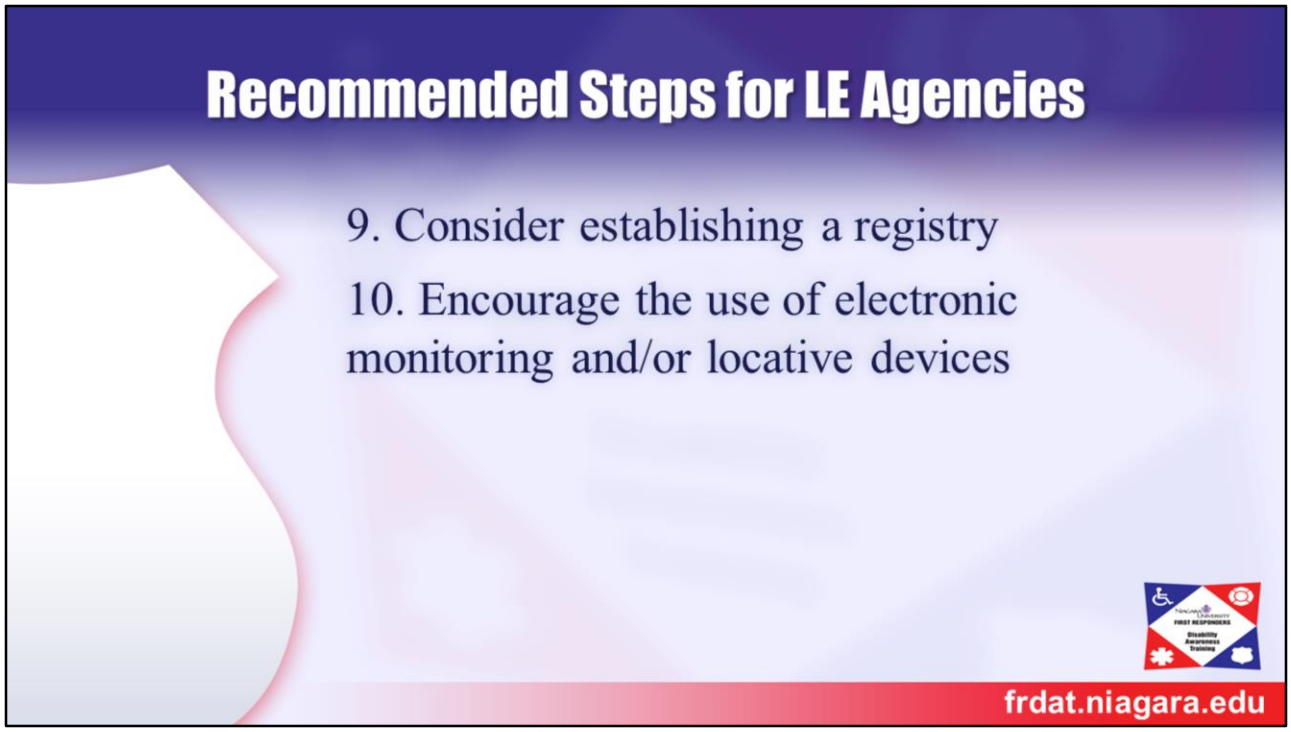
1. Alzheimer's Association of Virginia Resources

Source: The Alzheimer's Aware project from the Center for Public Safety and Justice (Univ of Illinois) funded by the Bureau of Justice Assistance

- The entire guide is included in your manual
- The Chief or Sheriff need to take the lead on the initiative, which includes personnel getting trained in this program
- Team should include front-line officers, administration, non-sworn staff, dispatch, and (ideally) someone from the Alzheimer's Association and/or a professional in the field of Dementia
- An advisory committee would have community partners (e.g. Alzheimer's Assn, medical professional, Office of Aging, caregiver, Service provider). This is imperative to a successful program

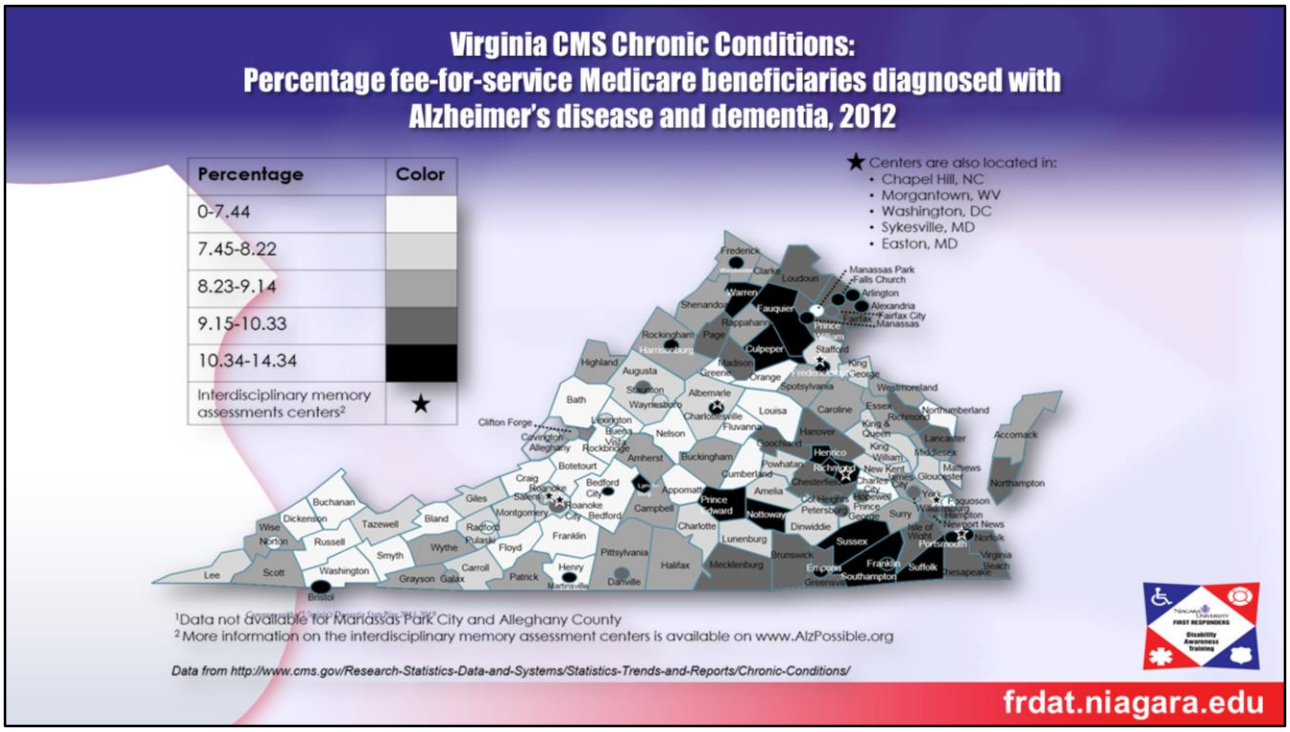


5. It is expected that you will be providing this training. There are other programs available beyond this
6. Have the handouts and additional resources as well as the agencies and associations' websites and information available for personnel.
7. Look to adopt the IACP model policy or some version for your department
8. The community needs to know what the PD/SO offers, their proactive initiative, and the fact officers are trained.
Provide information on programs such as Safe Return and Project Lifesaver, neighborhood canvasing, and workshops for caregivers and individuals

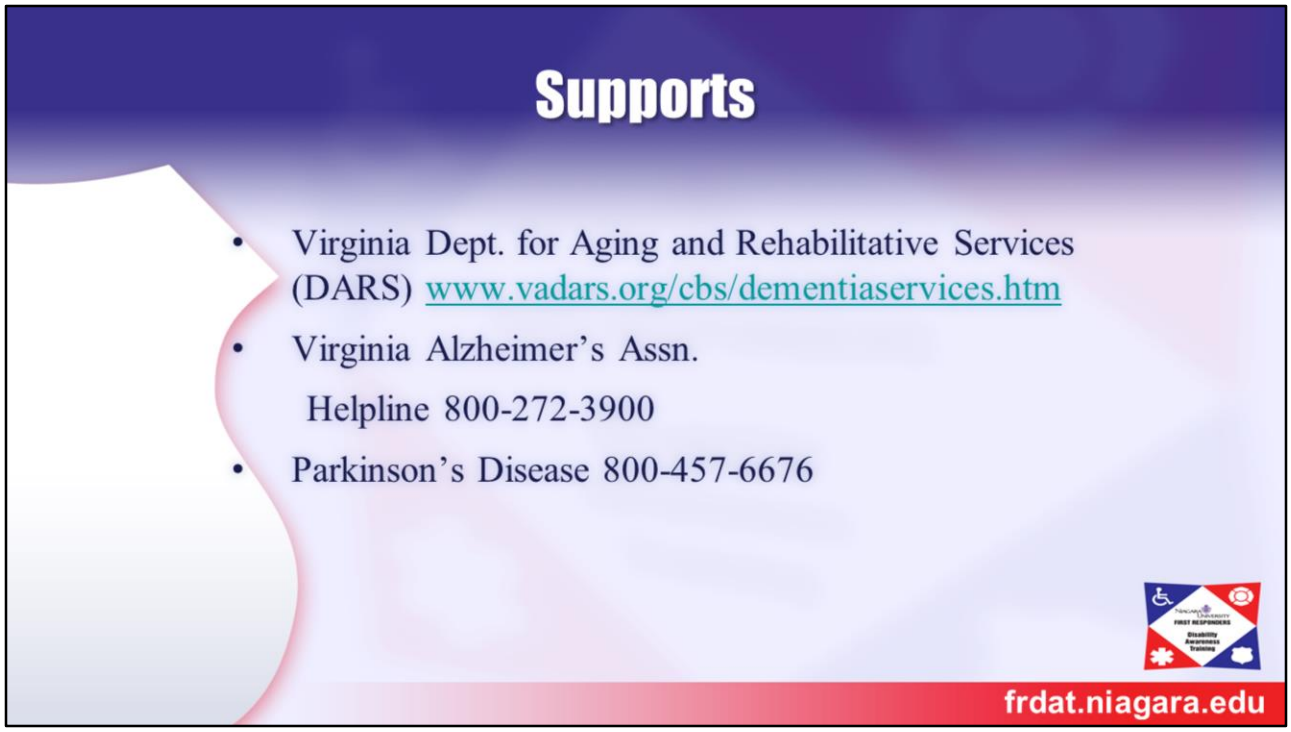


9. Individuals would go into a registry so officers have information (contact, address, description) in the event they wander or cause an incident in public.
10. Many people do not know about Project Lifesaver, Safe Return, other programs or understand the LE agencies role with devices.
Explain how it works and encourage their use.

- A biomarker is a biological factor that can be measured to indicate the presence or absence of a disease, or the risk of developing a disease
- It is now believed that the onset is some 20 years prior to symptoms being evident
- Identifying Alzheimer's disease in three stages contrast with the 1984 criteria, which identified the dementia when symptoms were present.



The Commonwealth's breakdown related to Medicare beneficiaries



- The VA Alzheimer's Association has a plethora of supports to include care counseling, support groups, early stage programs, and activities (to name a few)
- You may be encouraging caregivers to access the Assn. Do not assume that everyone is aware of their services.
- While some may be aware of their services, they may benefit from them. This may come to play if you are making frequent visits to a residence.

CLICK AND READ 4 BULLETS

- Encourage your audience to go to Niagara University's website for updates, information, review of the material they learned about today, and to register for the e-newsletter.
- The First Responders office is there for you, please use them for any question you may have, input you can provide, or assistance you may need, professionally or personally.
- Mention the FR-DAT Facebook page. This is continually updated with useful stories and information regarding disability awareness.


DEPARTMENT OF CRIMINAL JUSTICE SERVICES
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Virginia Department of Behavioral Health & Developmental Services
Virginia Board for People with Disabilities
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