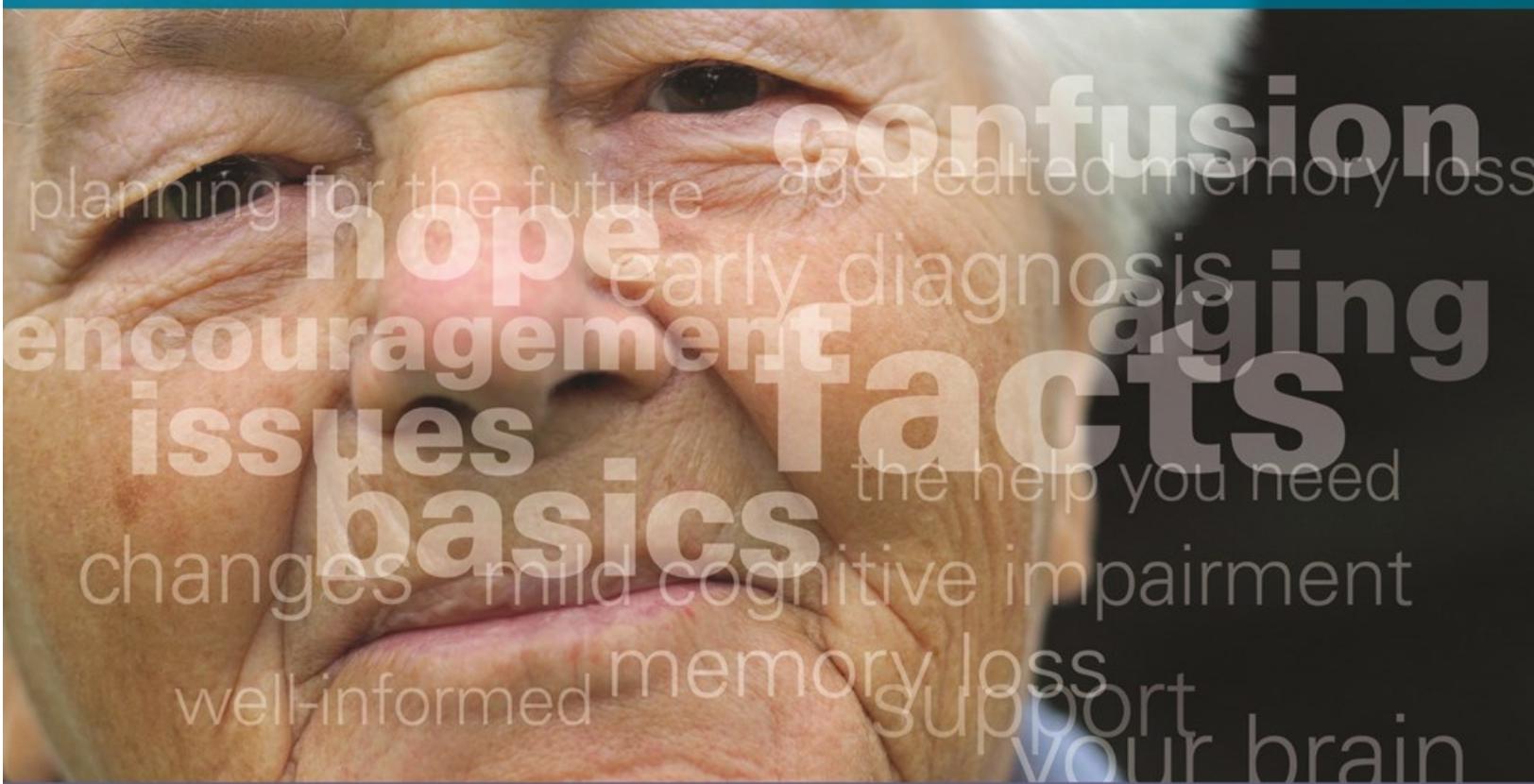


1 and 2 hour versions

# the basics

memory loss, dementia  
and alzheimer's disease



**Alzheimer's disease and related dementias are not a normal part of aging.**

The Basics: Memory Loss, Dementia and Alzheimer's Disease is a workshop, presented by the Alzheimer's Association, for anyone who would like to know more about Alzheimer's disease and related dementias.



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## introduction

The Alzheimer's Association's program, *The Basics: Memory Loss, Dementia and Alzheimer's Disease*, is intended to be presented to a general, mixed audience. It is run as a PowerPoint slide presentation, and is accompanied by a curriculum that may be printed and utilized as a reference.

This is a program that is designed to be delivered in both One Hour and Two Hour versions, with separate PowerPoints and Curricula for each. The program provides a topic overview, and detailed discussions of any of the dementias can be offered as follow-up programs. Participants wishing to learn more about any of the topics covered may be referred to those programs and/or additional resources.

*The Basics: Memory Loss, Dementia and Alzheimer's Disease* was developed in conjunction with a workgroup representing chapter offices throughout the country. The Alzheimer's Association would like to thank the following individuals who participated in the development of the program:

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Our sincere thanks go to our gracious Early Stage Advisory Group members and their spouses, who have been so candid and generous with their thoughts and feelings in our videos. The participants in this project include:

Betsy Anderson  
Stephen Hume  
Laura Jones  
Katherine (Kitty) Kennedy  
Joyce Simons

And our thanks to our medical experts in these videos as well:

Monica Parker, MD, Geriatric Medicine specialist at Emory University

Ron Petersen, MD, PhD, Director of the Mayo Alzheimer's Disease Research Center and Chair of the Alzheimer's Association's Medical and Scientific Advisory Council



## instructions

*The Basics* is a program that offered as a PowerPoint with embedded video in both One and Two Hour Versions. The text of both versions is contained in one Curriculum document. *The Basics* tools also include handouts for both One and Two Hour versions, and each has handouts containing two, three or six slide views per page.

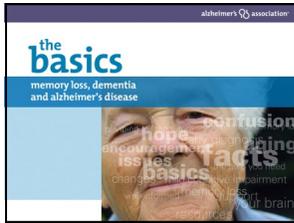
Each of the videos in *The Basics* is presented in two slides, with the first containing a photo of the person to cue the presenter to introduce the video. The second slide contains the video and it will auto-launch when the presenter advances to this slide, either on the laptop itself or by using a remote control. Note that the video slides are only presented as one slide in the handouts, so slide numbers will not match your PowerPoint or this Curriculum.

As with all Constituent Education Programs, this program is best offered by using the PowerPoint Viewer to provide the slides and videos. Instructions for using PowerPoint Viewer are available in the “Presenter Tools” section of the Education Programs page on Insite. The instruction document is titled “Download and View PowerPoint Presentations”.

Promotional tools are also available in the same section of Insite, as are links to the e-learning site and an “Evidence-Based Citations” document.



## 1 hour version



### Slide 1

Welcome to the Alzheimer's Association's *The Basics: Memory Loss, Dementia and Alzheimer's Disease* program. This program is designed to provide you with the basic information that everyone needs to know about memory loss issues and what they mean for all of us.



### Slides 2 and 3

#### **Film Clip Intro:**

Throughout this program, you will see video clips of people whose lives are directly affected by Alzheimer's disease in its earliest stages. You'll also get to hear from some of the nation's leading medical experts in the area of memory loss and aging.

Dr. Ron Petersen is the Director of the Alzheimer's Disease Research Center at Mayo, and is the Chair of the Alzheimer's Association's Medical and Scientific Advisory Council. In our first video clip, Dr. Petersen provides some perspective on the impact of Alzheimer's disease.

#### **View film clip**

#### **Presenter's note:**

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- As baby boomers age, huge numbers of people enter the period of increased risk for Alzheimer's disease.

- Some of those people will develop the disease, and the impact of those numbers will bankrupt our current medical care system unless medications are found to slow the disease progression.

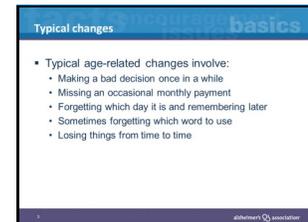
### **Slide 4**

As we age, our bodies age with us -- and so do our brains. Just as we experience changes in our bodies that make it harder for us to move, lift and run in the ways we once did, our brains lose some of the agility they once had.

On this slide, you can see some of the sorts of changes that typically come with the aging process. These changes are not considered to indicate a problem; they just indicate that your brain is aging right along with the rest of your body.

The changes that come with typical aging are different than the changes associated with Alzheimer's disease.

If you have typical age-related memory loss, you may have had an experience where you know that there is something you need to do but cannot remember what it is. You try, but just cannot come up with it right away. Often you will remember what it was if you wait a little while. If a person with Alzheimer's can't remember something in the present, he or she will rarely remember it later.



### **Slides 5 and 6**

#### **Film Clip Intro:**

In this video clip, Joyce describes some of the changes she noticed in herself that are not typical of the aging process and caused concern.

#### **View film clip**

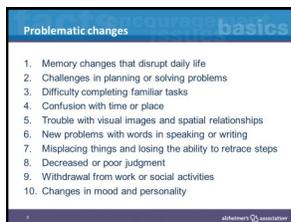


**Presenter's note:**

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- The kinds of signs that Joyce noticed were not what people typically experience with advancing age.
- Her symptoms were a cause for concern and signaled the need to see a doctor.



**Slide 7**

With Alzheimer's disease, unlike with age-related memory loss, the changes are not "once in a while" occurrences, but are consistent and ongoing patterns of loss of function in skill areas that were once reliable.

The Alzheimer's Association's *Know the 10 Signs* campaign urges early detection of Alzheimer's disease in order to be able to intervene as early in the disease process as possible. Anyone who notices any of these problematic signs in themselves or someone else needs to get a doctor involved for a thorough examination to see what the cause of the symptoms is and what to do about it.

Here are the 10 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 at home, at work or at leisure
4. Confusion with time or 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

You can get more information about the warning signs in the Alzheimer’s Association’s program, Know the 10 Signs: Early Detection Matters, which is available online at [training.alz.org](http://training.alz.org).

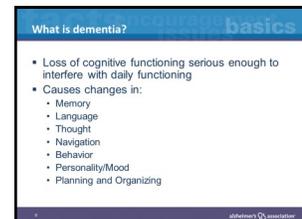
**Presenter’s note:**

*This is a good time to promote upcoming Know the 10 Signs program presentations as well. Flyers about the programs can be distributed and/or available on the resource table.*

**Slide 8**

Let’s move to talking about dementia, which is very different from typical aging, and look at how it relates to Alzheimer’s disease.

Dementia can affect a person’s entire range of thinking abilities. Although memory changes are often involved, it is important to realize that many other areas of thought **and behavior** can also be affected. **The losses that take place build as the dementia disease progresses, and they will eventually affect basic functions like walking, speaking and eating. Eventually, dementia compromises the body’s ability to breathe and swallow and in the late stage, diseases causing dementia are fatal.**



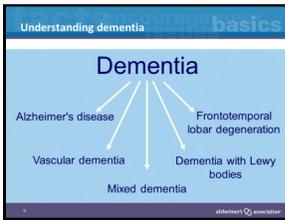
**Slide 9**

There also are some **diseases or conditions that mimic dementia** and are **reversible**. If the symptoms are due to a reversible condition, the cause may be treated and the symptoms may diminish or disappear completely. Determining which changes are reversible and which are not requires an evaluation by a primary care doctor or specialist.



Reversible diseases or conditions mimicking dementia include:

- Depression
- Metabolic problems (like an underactive thyroid)
- Adverse reactions to medication
- Infections (like pneumonia)
- Brain tumors
- Sensory loss
- Serious nutritional deficiencies (like too little Vitamin B12)
- Alcohol and drug reactions
- Dehydration



### Slide 10

The word “dementia” is like the word “food” – it is an umbrella term, and many different types. Dementia is not a disease, but a word that refers to a condition (sometimes called a syndrome) that can be caused by many diseases.

The term “dementia” is used to refer to the symptoms that occur when the brain is affected by a specific disease or medical condition that causes a decline in cognitive functioning. This decline is significant enough to interfere with daily life, causing a loss of functioning in areas of thoughts and behavior that were not a problem in the past.

Dementia diseases are **progressive**, which means the symptoms will gradually get worse over time. How fast some types of dementia progress depends on the individual. Each person is unique, and how each of them may experience dementia and its symptoms will be different.

**Alzheimer’s disease** is the **most common form of dementia**. Alzheimer’s accounts for **60-80 percent of all cases** of dementia in Americans aged 71 and older, and we’ll discuss the details shortly. First, let’s look at some less common dementia diseases.

Other forms of dementia include the diseases listed below.

- **Vascular dementia** is less common as the sole cause of dementia than Alzheimer's, accounting for only up to about 10 percent of dementia cases. However, it is very common in older people with dementia, with about 50 percent of people with dementia having evidence of vascular dementia at the same time as Alzheimer's. When this occurs, it is categorized as mixed dementia.
- Vascular dementia:
  - is characterized by impairment caused by reduced blood flow to parts of the brain, depriving nerve cells of food and oxygen.
  - can occur after a major stroke or a series of mini-strokes blocks blood flow to a large area of brain tissue.

**Presenter's note:**

Below are additional details to add if asked.

- Vascular dementia can cause symptoms similar to Alzheimer's disease, but are typically more related to impaired ability to make decisions, plan or organized rather than difficulty with memory.
- **Mixed dementia** is a condition in which Alzheimer's disease and another type of dementia, typically vascular dementia, occur together. As many as half of the people with Alzheimer's disease may actually have mixed dementia.

**Presenter's note:**

Below are additional details to add if asked.

- Data is beginning to emerge that suggest that the diagnosis of specific types of dementia may not be as clear cut as previously believed.

- Many physicians can diagnose Alzheimer's disease with a high level of accuracy, but when other dementias exist at the same time, it makes diagnosing more complicated.
- **Frontotemporal lobar degeneration (FTLD)**, formerly called frontotemporal dementia (FTD) includes dementias such as Pick's disease and primary progressive aphasia.
  - It is a more rare form of dementia
  - Personality changes and disorientation occur before memory loss.

***Presenter's note:***

Below are additional details to add if asked.

- Many cases of FTD have a younger onset, which means that they are diagnosable before the age of 65
- FTD progresses more quickly than Alzheimer's disease.
- The first symptoms of FTD often involve changes in personality, judgment, planning and social skills. They may:
  - Make rude or off-color remarks to family or strangers.
  - Make unwise decisions about finances or personal matters.
  - Show feelings that do not seem appropriate to the situation.
  - Have an unusually strong urge to eat and often gain weight as a result..
- **Dementia with Lewy Bodies (DLB)**, formerly called Lewy body disease (LBD) often starts with wide variations in attention and alertness.
  - 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.

**Presenter's note:**

Below are additional details to add if asked.

Additional symptoms include:

- Excessive daytime drowsiness.
- Detailed visual hallucinations.
- Mental symptoms and level of alertness that may fluctuate throughout the day, or may vary from one day to another.
- A sleep disorder involving people acting out their dreams, sometimes vividly or violently.

**Slide 11**

**Presenter's note:**

Below are details about these diseases that you may want to include if asked.



Other less common dementia diseases include:

- **Creutzfeldt-Jakob disease (CJD)** is another rare form of dementia and is rapidly fatal. It impairs memory and coordination, and causes behavioral changes. One specific form of the disease is believed to be caused by the consumption of products from cattle affected by mad cow disease.
- **Parkinson's disease** affects control of movement, resulting in tremors, stiffness and impaired speech. Many individuals with Parkinson's also develop dementia in later stages of the disease.
- **Huntington's disease** is an inherited progressive disorder that causes irregular movements of the arms, legs and facial muscles, personality changes and a decline in the ability to think clearly. This disease has a very clear genetic link.

- **Normal pressure hydrocephalus**, which is usually of unknown cause. Symptoms include difficulty walking, memory loss and inability to control urine. Sometimes NPH can be corrected with surgery to drain the excess fluid in the brain.
- **Wernicke-Korsakoff syndrome** is a two-stage disorder caused by a deficiency of thiamine (vitamin B-1). 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 doses of thiamine may reverse some of the damage.

**Visual processing disorders** related to dementia, traumatic brain injury or other forms of brain damage include:

- **Posterior Cortical Atrophy (PCA)**, in which the outer layer of the brain at the back of the head gradually and progressively deteriorates, causing visual processing difficulties.
- **Cortical Visual Impairment (CVI)** is a visual impairment that is caused by traumatic brain injury or other forms of brain damage. The difficulty that people with CVI have is not actually with the eyes, but rather with the brain’s inability to process visual stimuli accurately, and visual impairment is the result. Many people with CVI attempt to correct their vision with a series of eyeglass prescriptions that prove ineffective, eventually leading to a neurology appointment and a CVI diagnosis.

## Slide 12

Many people receive a diagnosis of a Mild Cognitive Impairment. Mild cognitive impairment (MCI) is a condition in which a person has problems with memory, language or another mental function severe enough to be noticeable to other people and to show up on tests, but not serious enough to interfere with daily life. Because the problems do not interfere with daily activities, the person does not meet criteria for a diagnosis of Alzheimer's or another a form of dementia.

Approximately 15-26 percent of people age 65 or older have MCI.

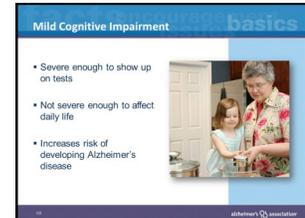
Research has indicated that individuals with MCI have an increased risk of developing Alzheimer's disease over the next few years, especially when their main problem is memory. More recent research, tells us that the brain changes associated with Alzheimer's may begin 20 or more years before MCI symptoms appear, leading the National Institute on Aging and the Alzheimer's Association to propose updating diagnostic criteria and guidelines for classifying Alzheimer's disease. Under this new system, Alzheimer's disease is seen as developing on a "continuum".

Research has also shown that 32 percent of individuals with MCI go on to develop Alzheimer's disease within five years. However, MCI can develop for reasons other than Alzheimer's, and MCI does not always lead to dementia. In some people, MCI reverts to normal cognition or remains stable. In other cases, such as when a medication causes cognitive impairment, MCI is mistakenly diagnosed. Therefore, it's important that people experiencing cognitive impairment seek help as soon as possible for diagnosis and possible treatment.\*\*

There is currently no treatment for MCI approved by the FDA.

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\*\* Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures





## Slides 13 and 14

In this clip, Steve describes early signs of dementia that he noticed in himself. Steve has Alzheimer's disease, which is the most common form of dementia.

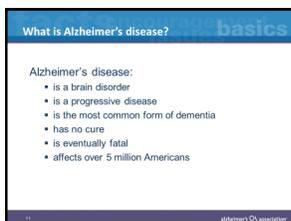
**View film clip**

### *Presenter's note:*

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- Steve's being frozen at his desk with no idea how to proceed is the kind of dramatic symptom that may be seen early in dementia.
- Some early symptoms that people experience are much more subtle.
- Everyone's experience with dementia is different.



## Slide 15

Now we'll spend some time looking specifically at Alzheimer's disease. In the United States alone, more than 5 million people live with Alzheimer's. Someone will develop Alzheimer's every **66** seconds. One out of nine over the age of 65, and one third over the age of 85 have the disease. **It is projected that by 2030, the segment of the U.S. population ages 65 and older will increase to 74 million older Americans, who will make up over 20 percent of the total population.\*\***

Alzheimer's is a disease of the brain that causes problems with memory, thinking and behavior. It is not a normal part of aging. Although symptoms can vary widely, the first problem people typically notice is forgetfulness severe enough to affect their ability to function at home or at work, or to enjoy lifelong hobbies.

Today we know that:

**Alzheimer's disease is a progressive and fatal brain disease.** Alzheimer's destroys brain cells, causing memory loss and problems with thinking and behavior severe enough to affect work, lifelong hobbies or social life. Alzheimer's gets worse over time, and it is fatal. Today it is the sixth-leading cause of death in the United States.

Although Alzheimer's disease has no current cure, treatments for symptoms, combined with the right services and support, can make life better for the millions of Americans living with Alzheimer's. There is an accelerating worldwide effort under way to find better ways to treat the disease, delay its onset or prevent it from developing.

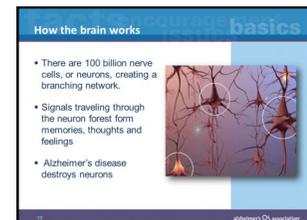
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\*\* Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures

### Slide 16

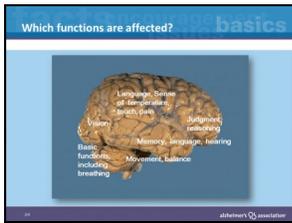
To understand how Alzheimer's disease affects our brains, let's look at how the brain works. The brain has approximately 100 billion nerve cells, which are called neurons. Each neuron connects to many others to form communication networks. In addition to neurons, the brain includes cells specialized to support and nourish it.

Groups of neurons have special jobs. Some are involved in thinking, learning and memory. Others help us see, hear and smell. Still others tell our muscles when to move. To do their work, brain cells operate like tiny factories. They receive supplies, generate energy, construct equipment and get rid of waste. Cells also process and store information and communicate with other cells. Keeping everything running requires coordination, as well as large amounts of fuel and oxygen.



Scientists believe that Alzheimer’s disease prevents parts of the cell’s “factory” from running well. They are not sure where the trouble starts. Just like in a real factory, backups and breakdowns in one system cause problems in other areas.

In the brain, the process occurs in a similar way. Brain cells lose their ability to do their jobs and eventually die, resulting in shrinkage of the brain. The damage spreads and two abnormal structures called plaques and tangles are prime suspects in damaging and killing nerve cells.



### Slide 17

The destruction of brain cells caused by Alzheimer’s systematically moves through the brain, first damaging the language and memory sections of the hippocampus, which is located in the temporal lobe. As the disease progresses, it continues to destroy neurons in regions of the brain that control other functions as well. Multiple regions can be affected simultaneously.

As Alzheimer’s progresses, individuals may experience changes in personality and behavior, and have trouble recognizing friends and family members. It then moves on to affect judgment and movement (the frontal lobe), visual processing (the occipital lobe) and movement, orientation, recognition and perception of stimuli (the parietal lobe).

In advanced Alzheimer’s disease, most of the cerebral cortex (which contains all of the lobes) is seriously damaged. Individuals lose their ability to communicate, to recognize loved ones and to care for themselves.

In the final stages, the section of the brain controlling our most basic functions (the brain stem), like breathing and swallowing, is damaged.

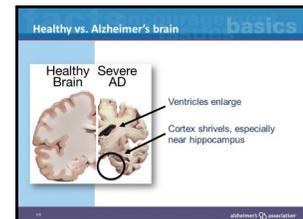
Alzheimer's disease can last up to 20 years from onset of symptoms, and the average life expectancy after onset of symptoms is 4-8 years.\*\*

The length of time that the disease lasts depends in part on age at diagnosis and whether a person has other health conditions.

\*\* Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures

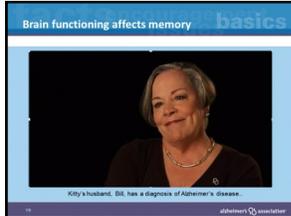
### Slide 18

Here is a comparison view of how massive cell loss changes the whole brain in advanced Alzheimer's disease. Notice the big difference in size between the two brains. What you are seeing is atrophy, or shrinkage, due to cell death in the late stages of Alzheimer's disease.



On the left is a typical adult brain.

In the Alzheimer brain, on the right, the cortex shrinks and shrivels up as the result of damage to the neurons, damaging areas involved in thinking, planning and remembering. Shrinkage is especially severe in the hippocampus, an area of the brain that plays a key role in formation of new memories and is sometimes known as the “memory bank.” You can also see the ventricles pointed out in this slide. These fluid-filled spaces within the brain grow larger as the disease progresses, neurons die, and the brain rids itself of dead tissue. These areas are no longer able to do the jobs they once did, resulting in loss of cognitive function.



## Slides 19 and 20

### **Film Clip Intro:**

In this video clip, Kitty talks about seeing changes in her husband Bill that had to do with problems with the formation of new memories in the brain.

### **View film clip**

### *Presenter's note:*

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- Kitty's example of this process of memory formation being altered in her husband, Bill, demonstrates how profound this effect can be.
- She says that the lack of sleep caused him to lose the previous day. There is evidence that suggests a connection between sleep and memory storage, and this effect may be more pronounced in people with Alzheimer's disease. The research on this topic is continuing to emerge.



## Slide 21

While scientists know Alzheimer's disease involves progressive brain cell failure, they have not yet identified any single reason why cells fail. However, they have identified certain risk factors that increase the likelihood of developing Alzheimer's.

### **Age**

The greatest known risk factor for Alzheimer's is increasing age. Most individuals with the disease are 65 or older. The likelihood of developing Alzheimer's doubles about every five years after age 65. After age 85, the risk reaches nearly 32 percent. \*\*

\*\* Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures

### **Gender**

More women than men have Alzheimer's disease and other dementias. Almost two-thirds of Americans with Alzheimer's are women, and among people age 71 and older, 16 percent of women have Alzheimer's disease and other dementias compared with 11 percent of men. But the reasons for this are not entirely clear.

#### ***Presenter's note:***

The most commonly held view has been that the difference is due to the fact that women tend to live longer than men and older age is the greatest risk factor. New research suggests that risk could be higher for women due to biological or genetic variations, or even different life experiences related to education and occupational choices. More research will need to be done to clarify the causes of this gender difference.

### **Race and Ethnicity**

A review of many studies conducted by an expert panel concluded that older African-Americans are about twice as likely to have Alzheimer's and other dementias as older whites. The rate for older Hispanics is about one and a half times the rate for older whites. These differences appear to be primarily related to health, lifestyle and socioeconomic risk factors across racial and ethnic groups.

### **Down syndrome**

Individuals with Down syndrome develop the pathological features and symptoms of Alzheimer's disease in middle age or older adulthood at a much higher rate than the general population, usually beginning in their 40s.

### **Family history**

Another risk factor is family history. Research has shown that those who have a parent, brother, sister or child with Alzheimer's are at a higher risk to develop Alzheimer's. The risk further increases if more than one family member has the illness. When diseases tend to run in families, either heredity (genetics) or environmental factors or both may play a role.

### **Genetics (heredity)**

Scientists know genes are involved in Alzheimer's. There are two categories of genes that can play a role in determining whether a person develops the disease. One gene increases the risk of developing Alzheimer's. Another much more rare situation is one in which the genetic structure is deterministic, meaning if you have that set of genes, **you have a 95% chance of developing** Alzheimer's. There are only a few hundred cases like this in the world.

When Alzheimer's disease is caused by deterministic genes, it is called "familial Alzheimer's disease," and many family members in multiple generations are affected. True familial Alzheimer's accounts for less than 1 percent of cases.

Genetic tests are available for both APOE-e4 and the rare genes that directly cause Alzheimer's. However, health professionals do not currently recommend routine genetic testing for Alzheimer's disease. Testing for APOE-e4 is sometimes included as a part of research studies.

### ***Presenter's note:***

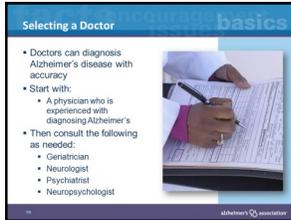
*Refer interested attendees to the Genetics Fact Sheet and other risk factor material.*

**Head injury:** There appears to be a strong link between serious or repeated head injury and future risk of Alzheimer's. People can reduce their risk of developing Alzheimer's disease by protecting their heads from injury.

**Heart-brain connection:** Some of the strongest evidence links brain health to heart health. The risk of developing Alzheimer's or vascular dementia appears to be increased by high blood pressure, heart disease, stroke, diabetes and high cholesterol. Because certain ethnic groups, such as African-Americans and Hispanics, have a higher rate of developing these conditions, particular attention needs to be paid to diet, physical activity, and medical care in order to reduce the chance of developing vascular problems. Work with your doctor to monitor your heart health and treat any problems that arise.

**General healthy aging:** Other lines of evidence suggest that strategies for overall healthy aging may help keep the brain healthy, and may even offer some protection against developing Alzheimer's or related diseases. Try to keep your weight within recommended guidelines and eat a healthy diet, avoid tobacco and excess alcohol, stay socially connected, and exercise both your body and mind. There is no magic bullet like broccoli or crosswords that is guaranteed to prevent Alzheimer's disease. Though scientists have not yet discovered anything to prevent you from getting Alzheimer's, these things may reduce your risk.

**Memory screening tools** are found in many health fairs, and can even sometimes be purchased online. If you have a question about how you or someone you care about is functioning with regard to memory or thinking, the Alzheimer's Association recommends prompt and thorough evaluation by a doctor. It is important to identify the actual cause of the concern or symptom in order for the person to receive proper care and treatment. One reason for people who suspect dementia to get a diagnosis is so the physician can look for causes of cognitive decline, other than Alzheimer's disease, that may be treatable or reversible. But another reason is so that a potentially life-threatening condition can be diagnosed and treated, and the symptoms reduced or eliminated.



## Slide 22

When symptoms appear in anyone, it's time to arrange a thorough diagnosis to find out what is going on. This process may seem overwhelming at first, but taking the first step is important to help determine what needs to be done. Let's look at how to get the process started.

Contrary to what used to be true, doctors can now diagnose Alzheimer's disease and other dementias with a great deal of accuracy, given particular tests and diagnostic skills. Studies that determine how prevalent the disease is test all participants for the presence of Alzheimer's disease, but in the community, only about half of those with the disease have been told that they have it by a physician.

There is no single type of doctor who specializes in diagnosing and treating memory loss or Alzheimer's disease. Many people contact their regular primary care physician or internist about their concerns. Primary care doctors often oversee the diagnostic process and provide treatment themselves, but referrals may also be made to any of the specialists listed on this slide.

The first step in following up on symptoms is finding a doctor with whom you feel comfortable. People who have pursued a diagnosis report that they are most likely to be satisfied by seeing someone who:

- Is well informed about Alzheimer's disease.
- Has a great deal of experience with diagnosing people with memory problems.
- Is comfortable with age-related concerns.

Another option is to contact an Alzheimer's disease center (ADC) at major medical institutions nationwide. There are about 30 of these centers in the United States, funded by the National Institute on Aging. Many centers offer patients and families:

- Diagnosis and medical management information about the disease.
- Services and resources.

- Opportunities for volunteers to participate in drug trials and other clinical research projects.
- Support groups and other special programs for volunteers and their families.

**Presenter's note:**

*This is a good spot to mention the chapter's resource listing of diagnostic centers and local hospitals.*

**Slide 23**

Some items you should bring to your visit include:

- A list of symptoms, when they began and how frequently they occur, documented in the form of a journal or the use of care logs.
- A list of past and current medical problems.
- A list of all current medications, herbal remedies, and dietary supplements.
- At least one close family member or friend who can help describe your symptoms and help listen to what the doctor will tell you.

**Presenter's note:**

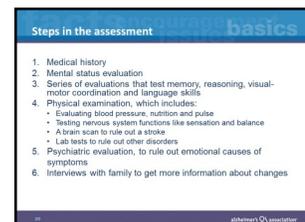
*You may want to refer to and hand out Preparing for Your Doctor's Visit checklists, care logs, etc., at this point in the presentation.*



**Slide 24**

Because there is no single test for Alzheimer's, diagnosis usually involves a thorough medical evaluation which includes:

1. **Medical history**, in which information about current mental or physical conditions, prescription and nonprescription medication use, and family health history is collected.
2. **Mental status evaluation** to assess sense of time and place; ability to remember, understand and communicate; and ability to do simple math problems.





You may want to ask the doctor to explain:

- Why the diagnosis is Alzheimer's.
- Where you or the person you care for may be in the course of the disease.
- What to expect in the future.

### **Slide 26**

Once the diagnosis of Alzheimer's disease is made, emotions run high. There are a lot of feelings that come up very suddenly and it's natural to feel overwhelmed. It is possible, though, to take control and channel some of those emotions into seeking support and education and to start planning for the future. Grief often plays a role in some of the emotions caregivers may be feeling. Sometimes people do not recognize that the frustration or annoyance they are experiencing toward the person with dementia is really grief over the everyday losses of the disease. Some people who have been searching for a diagnosis for a period of time actually feel some relief when they finally get a definitive reason for their cognitive decline.



### ***Presenter's note:***

*The conversation can get very personal and involved when emotions are being discussed. Some in the audience may want to ask questions or vent about things that are specific to their situations. These issues are important to them and should get addressed, but may not be best dealt with in a public dementia education program.*

*When you feel that the discussion has moved past the point where most people can relate to the audience member, it's a good idea to refer them to chapter services, and to the Association's national Helpline (800.272.3900) for 24/7 support.*

*The Caregiver Stress Check at [alz.org](http://alz.org) can be a helpful tool here as well.*



## Slide 27

In each individual, the course of Alzheimer's disease is different. Some people with the disease become more agitated, while others get more calm and even-tempered. The most pronounced changes early on in the disease may be about mood, memory or getting lost. But beyond the specifics of how each person functions with Alzheimer's disease, there are some general statements that can be made about how the disease progresses and what can be expected at each of these stages.

Sometimes, these stages are numbered one through seven, with Stage One being no impairment at all, and Stage Seven being the very end stage of the disease, which ultimately ends with death. Another way to categorize the progression of Alzheimer's disease, and the one we'll use today, is to talk about three stages of Alzheimer's disease: early stage (or mild Alzheimer's), middle stage (or moderate Alzheimer's) and late stage (or severe Alzheimer's). It's important to keep in mind that each individual's progression through the disease is different, and people may appear to be in a number of different stages at any given time. Which stage the person is in matters far less than understanding how the person is functioning and how to make accommodations for his or her needs. As the disease progresses from one stage to the next, attention will need to be paid to keeping the person safe and to retaining a sense of self.

Keeping in mind that each person's experience will differ, let's take a quick look at the early, middle and late stages of the disease.

Recent memory loss is the hallmark of early-stage, or mild, Alzheimer's disease. The person in the early stage of the disease may have difficulty managing money, driving, or handling social conversations as they once had. These behaviors represent a shift from the person's previous state, and the changes are noticeable to those closest to them.

# FACTS Encouragement basics

The middle stage involve greater difficulty with written and spoken language. People in this stage may get lost in familiar settings, and may have problems with keeping track of personal items, which results in accusing others of taking things from them. They may become confused about the day of the week or the season, causing them to dress in clothing that is inappropriate for the weather. They often require assistance with managing personal grooming in the middle stage of the disease as well.

In the late stage of Alzheimer's disease, both short-term and long-term memory are affected. Language is reduced to basic words or sounds, and communication with the person is carried out with using short sentences and gestures. Ultimately, the person in the late stage of the disease becomes completely dependent on caregivers to take care of all tasks, and care must be provided around the clock.

Throughout all of these stages, it is the job of the care partner or caregiver to help the person retain his or her sense of self and dignity. Even at the end of life, the person with Alzheimer's disease may feel comforted by touch, sound and taste. Providing those sensations allows the person to connect with others and continue to relate to his or her surroundings.

## **Presenter's note:**

*The Alzheimer's Association's brochure, [Basics of Alzheimer's Disease: What It Is and What You Can Do](#), provides more information about the stages and currently available treatments. It is helpful to provide your audience with copies of this brochure.*

## **Slides 28 and 29**

### **Film Clip Intro:**

In this next video, Dr. Monica Parker, a geriatrician with Emory University, talks about the need to make plans for the future early in the disease process.



**View film clip**

**Presenter's note:**

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- Dr. Parker stresses the need for making plans for parents before those arrangements become urgent needs.
- We need to be sure that we do the same for ourselves and for others closest to us.



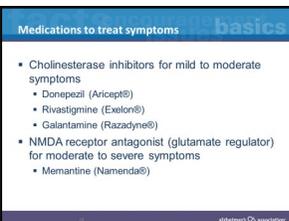
**Slide 30**

In the early stages, it's important for a person with Alzheimer's disease to make decisions with family members about his or her future care.

This helps everyone in a couple of important ways:

- It allows arrangements to be made to provide for the person with the disease before they are urgently needed and other issues may force decisions to be rushed.
- It also allows the person living with the disease to make plans that fit with his or her preferences and to maximize control over the future.

There are some medications that can be helpful to people in the early stages of Alzheimer's disease.



**Slide 31**

Currently, there is no cure for Alzheimer's and no way to stop the underlying death of brain cells. But drugs and non-drug treatments may help with both cognitive and behavioral symptoms.

Two types of drugs are currently approved by the U.S. Food and Drug Administration (FDA) to treat cognitive symptoms of Alzheimer's disease.

The first type, cholinesterase (*KOH-luh-NES-ter-ays*) inhibitors, is designed to prevent the breakdown of acetylcholine (*a-SEA-til-KOHlean*), a chemical messenger important for memory and learning. By keeping levels of acetylcholine high, these drugs support communication among nerve cells. They delay worsening of symptoms for six to 12 months for about half of the people who take them.

Three cholinesterase inhibitors are commonly used to treat mild to moderate Alzheimer's:

- Donepezil (Aricept<sup>®</sup>), approved in 1996, now used to treat all degrees of Alzheimer's (mild, moderate and severe).
- Rivastigmine (Exelon<sup>®</sup>), approved in 2000 for mild to moderate Alzheimer's.
- Galantamine (Razadyne<sup>®</sup>), approved in 2001 for mild to moderate Alzheimer's.

In 2014, a medication combining Namenda and Aricept was released. Called Namzaric, this medication is designed for people with moderate to severe Alzheimer's-related dementia who are already on stable doses of Namenda and Aricept.

The second type of drug works by regulating the activity of glutamate, a different messenger chemical involved in information processing:

- Memantine (Namenda<sup>®</sup>), approved in 2003 for moderate to severe Alzheimer's.

Memantine is the only currently available drug in this class, and may temporarily delay the worsening of symptoms for some people.



## **Slides 32 and 33**

### **Film Clip Intro:**

Here is Dr. Petersen to describe how medications can be helpful.

### **View film clip**

### ***Presenter's note:***

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- Dr. Petersen makes the point that the medications that are currently available will not change the outcome of the disease. It will still progress.
- Medications can be useful during the course of the disease, with positive short-term effects on behavior and cognition.



## **Slide 34**

Over the last 15 years, scientists have made enormous strides in understanding how Alzheimer's disease affects the brain. Many recent insights point toward promising new strategies for treatment, prevention and diagnosis.

When it comes to the most current thinking about treatments for Alzheimer's disease, researchers and experts currently don't expect a "magic bullet" that will do the job. Instead, they are looking at a combination of drugs that will function more like an AIDS or chemotherapy "cocktail." But in order for any drug to reach the market, it has to undergo a rigorous period of testing.

First, there is carefully documented laboratory work, which is followed by animal studies. Once the medication has been shown to be safe and effective there, new treatments must undergo clinical studies (testing in human volunteers, also called "clinical trials").

A broad range of drugs are in clinical trials now. These drugs impact biological processes associated with Alzheimer's. Involvement with a clinical trial can have a number of benefits:

- Contributing to the body of knowledge that will lead to eventual treatments and cures.
- Accessing the latest medications.
- Receiving a high standard of care.

Clinical studies are the engine that powers medical progress. Scientists work constantly to find better ways to treat diseases. Improved treatments can never become a reality without testing in human volunteers. No one ever chooses to become ill, but anyone can consider helping to advance knowledge about an illness affecting them or someone close to them. There are many clinical studies now recruiting participants with and without Alzheimer's disease to find better ways to treat the disease. No treatment being investigated can advance to the stage of clinical testing unless there is strong evidence indicating it will be as good as, or better than, the therapies that are currently available.

All participants receive regular care related to the study and opportunities to talk with study staff. Research shows that people involved in studies tend to do somewhat better than people in a similar stage of their disease who are not enrolled, regardless of whether the experimental treatment works. Scientists believe this advantage may be due to the general high quality of care provided during clinical studies.

You can find out more about clinical trials and how to get involved by visiting the Alzheimer's Association Web site at [www.alz.org](http://www.alz.org) and visiting our research page.



## Slide 35

No matter whether you want information or support; whether you have questions about memory loss or a dementia of any kind; or whether you are a professional, a researcher, a caregiver or a person diagnosed with Alzheimer's disease or another form of dementia, the Alzheimer's Association has resources for you and is available to help.

In addition to our live programs, we have a rich website at [alz.org](http://alz.org). Visit our website to get tips about finding and providing care, read about the latest research, and find the tools for your wellbeing. Spend some time exploring all we have to offer for you at [alz.org](http://alz.org).

One of the online tools that you'll find on our website is Alzheimer's Navigator. We can help you map out a plan to approach Alzheimer's by visiting the Web page at [alzheimersnavigator.org](http://alzheimersnavigator.org). Alzheimer's Navigator helps guide you to answers by creating a personalized action plan containing information, support and local resources. You can then share your plan with you friends and family, linking them to the materials customized for your situation.

By visiting our Community Resource Finder online tool at [communityresourcefinder.org](http://communityresourcefinder.org), you can search for local community living services, day programs, medical resources and more. Whether you are in the area or across the country, you can find services to help someone living with dementia and make the contacts you all need to ensure safety and comfort.

A rich supplement to our local supportive programs is ALZConnected, our online message boards with over 50,000 members who share their thoughts, questions and ideas with each other 24 hours a day. Whether you are

living with dementia or are close to someone who is, you can come on to read or post about your concerns. Let ALZConnected help you develop plans, find support and discover new coping techniques by connecting with others who are living with dementia or are partners in caring.

Our 24/7 Helpline offers dementia-trained professionals to talk with any time, day or night, every day of the year. Call us at 800.272.3900 when you need information about the disease and meeting its challenge, links to resources or a supportive ear during difficult times. We are here to help.

The Alzheimer's Association has chapters all through the country, where we offer education programs, support groups, and much more. To find a chapter anywhere in the U.S., go to [alz.org/findus](http://alz.org/findus), where you can search by state or zip code. Once on the chapter's web page, you can see what is being offered in that area.

Finally, the Training and Education Center of [alz.org](http://alz.org) is where you can access programs like this one from the convenience of home. Just go to [alz.org/training](http://alz.org/training), and you can find programs and materials that offer the most current information about dementia, treatments and care.

Please contact us and let the Alzheimer's Association partner with you to help ensure your wellbeing.

**Presenter's note:**

*Here is the spot to highlight what you are doing at your chapter, including upcoming programs, events and resources specific to the location of this presentation. Flyers and brochures from your chapter can be placed on the resource table along with the Know the 10 Signs and Principles for a Dignified Diagnosis materials.*



## **Slide 36**

You can use your voice, your motivation, your interest and your skills to help find new treatments and to enhance services for all people affected by dementia.

Clinical trials research studies are being conducted all over the world to find treatments that are safe and effective. Clinical trials are the best way for researchers to find new ways to detect, slow, treat and hopefully someday prevent Alzheimer's disease. The Alzheimer's Association's TrialMatch is a free clinical studies matching service that connects individuals with Alzheimer's, caregivers and healthy volunteers to local clinical trials seeking participants. When you join a clinical trial, you have an opportunity to participate in vital research that could change the course of Alzheimer's disease and improve the lives of all those it affects. Visit TrialMatch online at [trialmatch.alz.org](http://trialmatch.alz.org) or call our Helpline at 800.272.3900 to get started making a difference.

The Walk to End Alzheimer's and The Longest Day are opportunities for the local community to join together in the spirit of grassroots advocacy that is central to the mission of the Alzheimer's Association. Forming a team to support a friend or family member is a direct way to show your concern for the person as well as for the cause, and those who live with the impact of these diseases in their lives are tremendously grateful.

We also encourage you to join us in providing education and support programs to families in your area who are living with Alzheimer's and other forms of dementia. Whether you are a person with the disease, a care partner or caregiver, or a professional in the field, you can volunteer to use your knowledge and compassion to have a profound impact on those whose lives are affected by the disease.

*Presenter's note:*

*This is the time to highlight volunteer activities at your chapter and to circulate recruitment materials.*

You can also join us to speak up for the needs and rights of people with Alzheimer's and their families, and to help persuade state and federal Congress to increase funding for research and programs. Many caregivers and people with the disease find the experience of advocating to be therapeutic, and it puts a human face on complex policy issues for our legislators.

We need you to help us change the course of Alzheimer's disease for everyone affected, and we welcome you to join us in making a difference.

**Slides 36 and 37**

**Film Clip Intro:**

In our final film clip, Betsy describes the importance of building a network for yourself.

**View film clip**

*Presenter's note:*

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- It's important to build your network ahead of time, before you need it.
- You can't do it all and you can't do it alone.
- The Alzheimer's Association is here to help you and can be part of your care community.



# facts encouragement basics



## **Slide 38**

There are many ways to learn more about memory loss, dementia and Alzheimer's disease. No matter whether you want information or support; whether you have questions about memory loss or a dementia of any kind; or whether you are a professional, a researcher, a caregiver or a person diagnosed with Alzheimer's disease, the Alzheimer's Association has resources for you and is available to help. We look forward to hearing from you!

### ***Presenter's note:***

Here is the spot to highlight the education programs that will go into greater detail about Alzheimer's disease and caregiver issues.

*Add any final thoughts here.*

We have xx minutes left for any questions you might have.

### ***Presenter's note:***

*Take questions from the audience and remind them of upcoming programs and events, as well as the materials you have available. Remind them to fill out the evaluation sheets and turn them in to you.*

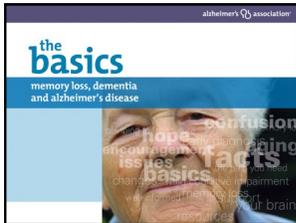


## **Slide 38**

(No text)



## 2 hour version



### Slide 1

Welcome to the Alzheimer's Association's *The Basics: Memory Loss, Dementia and Alzheimer's Disease* program. This program is designed to provide you with the basic information that everyone needs to know about memory loss issues and what they mean for all of us.



### Slides 2 and 3

#### **Film Clip Intro:**

Throughout this program, you will see video clips of people whose lives are directly affected by Alzheimer's disease in its earliest stages. You'll also get to hear from some of the nation's leading medical experts in the area of memory loss and aging,

Dr. Ron Petersen is the Director of the Alzheimer's Disease Research Center at Mayo, and is the Chair of the Alzheimer's Association's Medical and Scientific Advisory Council. In our first video clip, Dr. Petersen provides some perspective on the impact of Alzheimer's disease.

#### **View film clip**

#### **Presenter's note:**

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- As baby boomers age, huge numbers of people enter the period of increased risk for Alzheimer's disease.

- Some of those people will develop the disease, and the impact of those numbers will bankrupt our current medical care system unless medications are found to slow the disease progression.

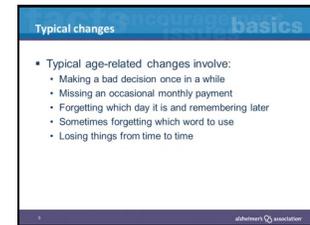
**Slide 4**

As we age, our bodies age with us -- and so do our brains. Just as we experience changes in our bodies that make it harder for us to move, lift and run in the ways we once did, our brains lose some of the agility they once had.



**Slide 5**

On this slide, you can see some of the sorts of changes that typically come with the aging process. These changes are not considered to indicate a problem; they just indicate that your brain is aging right along with the rest of your body.



The changes that come with typical aging are different than the changes associated with Alzheimer's disease.

If you have typical age-related memory loss, you may have had an experience where you know that there is something you need to do but cannot remember what it is. You try, but just cannot come up with it right away. Often you will remember what it was if you wait a little while. If a person with Alzheimer's can't remember something in the present, he or she will rarely remember it later.

**Slides 6 and 7**

**Film Clip Intro:**

In this video clip, Joyce describes some of the changes she noticed in herself that are not typical of the aging process and caused concern.



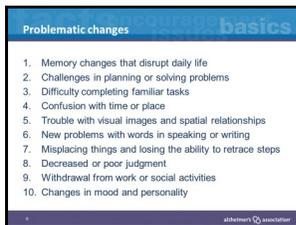
### View film clip

#### Presenter's note:

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- The kinds of signs that Joyce noticed were not what people typically experience with advancing age.
- Her symptoms were a cause for concern and signaled the need to see a doctor.



#### Slide 8

With Alzheimer's disease, unlike with age-related memory loss, the changes are not "once in a while" occurrences, but are consistent and ongoing patterns of loss of function in skill areas that were once reliable.

The Alzheimer's Association's *Know the 10 Signs* campaign urges early detection of Alzheimer's disease in order to be able to intervene as early in the disease process as possible. Anyone who notices any of these problematic signs in themselves or someone else needs to get a doctor involved for a thorough examination to see what the cause of the symptoms is and what to do about it.

Here are the 10 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 at home, at work or at leisure
4. Confusion with time or 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

The Basics 2 Hour Version updated 05.16

- 8. Decreased or poor judgment
- 9. Withdrawal from work or social activities
- 10. Changes in mood and personality

**Presenter's note:**

*This is a good time to promote upcoming Know the 10 Signs program presentations as well. Flyers about the programs can be distributed and/or available on the resource table.*

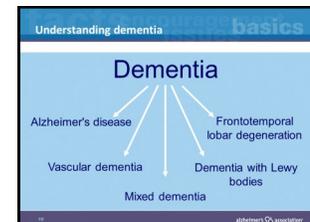
**Slide 9**

Let's move to talking about dementia, which is very different from typical aging, and look at how it relates to Alzheimer's disease.



**Slide 10**

The word “dementia” is like the word “food” – it is an umbrella term, and many different types. **Dementia is not a disease, but a word that refers to a condition (sometimes called a syndrome) that can be caused by many diseases.**



**The term “dementia” is used to refer to the symptoms that occur when the brain is affected by a specific disease or medical condition that causes a decline in cognitive functioning. This decline is significant enough to interfere with daily life, causing a loss of functioning in areas of thoughts and behavior that were not a problem in the past.**

**Dementia diseases are progressive, which means the symptoms will gradually get worse over time. How fast some types of dementia progress depends on the individual. Each person is unique, and how each of them may experience dementia and its symptoms will be different.**

**Alzheimer's disease** is the **most common form of dementia**. Alzheimer's accounts for **60-80 percent of all cases** of dementia in Americans aged 71 and older. Less common forms of dementia:

- Vascular dementia is less common as the sole cause of dementia than Alzheimer's, accounting for up to about 10 percent of dementia cases. However, it is very common in older people with dementia, with about 50 percent also having evidence of vascular dementia. When this occurs, it is categorized as mixed dementia.
- Other diseases and conditions, including Parkinson's disease, mixed dementia, Lewy body disease, frontotemporal dementia, Creutzfeldt-Jakob disease and normal pressure hydrocephalus, account for the remaining 20 percent.\*\*

The various types of irreversible conditions or diseases mimicking dementia have different symptoms.

We will learn more about the most common form of dementia, Alzheimer's disease, in a couple of minutes, but first let's look at the other types of dementias. Please keep in mind that each of these dementias may have symptoms that look like other forms of dementia, and only a physician who is familiar with diagnosing cognitive disorders in seniors can make an accurate diagnosis.

\*\* Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures



### **Slides 11 and 12**

In this clip, Steve describes early signs of dementia that he noticed in himself. Steve has Alzheimer's disease, which is the most common form of dementia.

**View film clip**

**Presenter's note:**

Please insert your own 1-2 sentence comment about the video clip here.

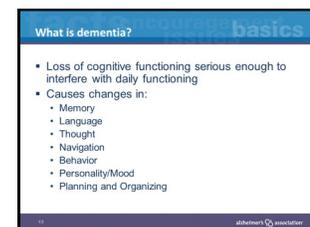
Important points from the film:

- Steve's being frozen at his desk with no idea how to proceed is the kind of dramatic symptom that may be seen early in dementia.
- Some early symptoms that people experience are much more subtle.
- Everyone's experience with dementia is different.

**Slide 13**

Dementia affects a person's entire range of thinking abilities. Although memory changes are often involved, it is important to realize that many other areas of thought can also be affected.

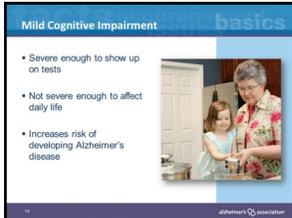
Remember that the person with dementia experiences loss of functioning in areas that were once performed without a problem. If the dementia is due to a reversible condition, the cause may be treated and the symptoms may diminish or disappear completely. But if the type of dementia is progressive, there is a gradual loss of skills and abilities that may have been taken for granted. These losses will eventually affect basic functions like walking, speaking and eating.



**Slide 14**

There also are some **diseases or conditions that mimic dementia** and are **reversible**. If the symptoms are due to a reversible condition, the cause may be treated and the symptoms may diminish or disappear completely. Determining which changes are reversible and which are not requires an evaluation by a primary care doctor or specialist.





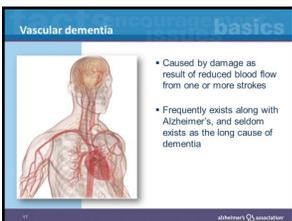
### Slide 15

Mild cognitive impairment (MCI) is a condition in which a person has problems with memory, language or another mental function severe enough to be noticeable to other people and to show up on tests, but not serious enough to interfere with daily life. Because the problems do not interfere with daily activities, the person does not meet criteria for a diagnosis of Alzheimer's disease or another form of dementia.

Past research has indicated that individuals with MCI have an increased risk of developing Alzheimer's disease over the next few years, especially when their main problem is memory. More recent research, tells us that the brain changes associated with Alzheimer's may begin 20 or more years before MCI symptoms appear, leading the National Institute on Aging and the Alzheimer's Association to propose updating diagnostic criteria and guidelines for classifying Alzheimer's disease. Under this new system, Alzheimer's disease is seen as developing on a "continuum".

Nearly half of all people who have visited a doctor with MCI symptoms will develop dementia in 3 or 4 years. However, not everyone diagnosed with MCI goes on to develop Alzheimer's, and MCI sometimes resolves on its own. It is unclear why some go on to develop Alzheimer's and others do not.

There is currently no treatment for MCI approved by the FDA.



### Slide 16

**Vascular dementia** is less common as the sole cause of dementia than Alzheimer's, accounting for about 10 percent of dementia cases. However, it is very common in older people with dementia, with about 50 percent also having evidence of vascular dementia. When this occurs, it is categorized as mixed dementia.

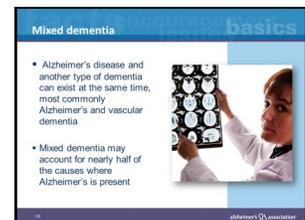
Vascular dementia is characterized by impairment caused by reduced blood flow to parts of the brain, depriving nerve cells of food and oxygen. This can occur after a major stroke blocks blood flow to a large area of brain tissue, or as the result of a series of small strokes that block the flow of blood through the arteries in the brain. As a result of this restricted blood flow, the brain may have damage that causes symptoms similar to Alzheimer's disease, but are typically more related to impaired ability to make decisions, plan or organized rather than difficulty with memory. Decline may occur in "steps," where there is a fairly sudden change in function rather than a more gradual decline over time. Symptoms include problems with memory, confusion and difficulty with instructions.

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.

### Slide 17

**Mixed dementia** is a condition in which Alzheimer's disease and another type of dementia, typically vascular dementia, occur together. Data is beginning to emerge that suggest that the diagnosis of specific types of dementia may not be as clear cut as previously believed, and that many individuals have more than one type operating at the same time. This type of "mixed dementia" may actually account for as many as half of the cases in which Alzheimer's disease is present. **Many physicians can diagnose Alzheimer's disease with a high level of accuracy. But when other dementias exist at the same time, it adds a degree of complexity to the diagnostic process.**

The decline seen with mixed dementia may follow a pattern similar to either Alzheimer's, vascular dementia or a combination of the two.



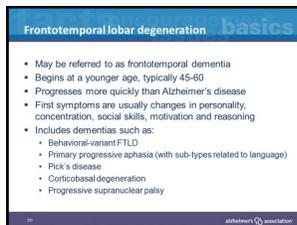


**Slide 18**

**Dementia with Lewy Bodies (DLB)**, formerly called **Lewy body disease (LBD)**, often starts with wide variations in attention and alertness. Symptoms are often similar to that of Alzheimer’s disease, but individuals affected by this illness often experience additional symptoms unique to Lewy bodies.

**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.
- Detailed visual hallucinations. (Some people are frightened by them while others react with indifference or are even aware of the unreality of the hallucination.)
- Mental symptoms and level of alertness that may fluctuate throughout the day, or may vary from one day to another.
- A sleep disorder involving people acting out their dreams, sometimes vividly or violently.



**Slide 19**

**Frontotemporal lobar degeneration (FTLD)** formerly called **Frontotemporal dementia (FTD)**, or , includes dementias such as Pick’s disease and primary progressive aphasia. It is a more rare form of dementia in which personality changes and disorientation occur before memory loss. Many cases of FTD have a younger onset, which means that they are diagnosable before the age of 65, and FTD progresses more quickly than Alzheimer’s disease.

The first symptoms of FTD 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 that do not seem appropriate to the situation and may seem either too excessive or too minimal. They may also have an unusually strong urge to eat and often gain weight as a result.

## Slide 20

**Creutzfeldt-Jakob disease (CJD)** is a rare form of dementia and is rapidly fatal. It impairs memory and coordination, and causes behavioral changes.

The three main categories of CJD are:

1. Sporadic CJD, which occurs for no known reason.
2. Hereditary CJD, which runs in families.
3. Acquired CJD, which occurs from contact with infected tissue, usually during a medical procedure. One specific form of the disease is believed to be caused by the consumption of products from cattle affected by mad cow disease.

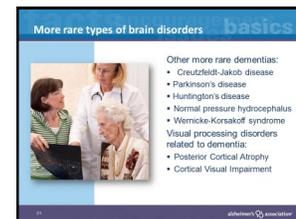
After the onset of symptoms, the disease progresses quickly and can be fatal within one year.

**Parkinson's disease** affects control of movement, resulting in tremors, stiffness and impaired speech. Many individuals with Parkinson's also develop dementia in later stages of the disease.

**Huntington's disease** is an inherited progressive disorder that causes irregular movements of the arms, legs and facial muscles, personality changes and a decline in the ability to think clearly. This disease has a very clear genetic link.

The cause of most cases is unknown. Symptoms include difficulty walking, memory loss and inability to control urine. Sometimes NPH can be corrected with surgery to drain the excess fluid in the brain.

**Wernicke-Korsakoff syndrome** is a two-stage disorder caused by a deficiency of thiamine (vitamin B-1). 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 doses of thiamine may reverse some of the damage.

**Visual processing disorders** related to dementia, traumatic brain injury or other forms of brain damage include:

- **Posterior Cortical Atrophy (PCA)**, in which the outer layer of the brain at the back of the head gradually and progressively deteriorates, causing visual processing difficulties.
- **Cortical Visual Impairment (CVI)** is a visual impairment that is caused by traumatic brain injury or other forms of brain damage. The difficulty that people with CVI have is not actually with the eyes, but rather with the brain’s inability to process visual stimuli accurately, and visual impairment is the result. Many people with CVI attempt to correct their vision with a series of glasses that prove ineffective, eventually leading to a neurology appointment and a CVI diagnosis.



## Slide 21

Now we’ll spend some time looking specifically at Alzheimer’s disease. As mentioned earlier, Alzheimer’s disease is the most common form of dementia. In the United States alone, more than 5 million people live with Alzheimer’s. Someone will develop Alzheimer’s every 68 seconds. **It is projected that by 2030, the segment of the U.S. population ages 65 and older will increase to 74 million older Americans, who will make up over 20 percent of the total population.\*\***

\*\* Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures

### **Slides 22 and 23**

When people first come face-to-face with the diagnosis of Alzheimer's disease, they often realize that even though there are so many others with the diagnosis, they are very unfamiliar with the disease. Laura describes this in our next video clip.



### **View film clip**

#### ***Presenter's note:***

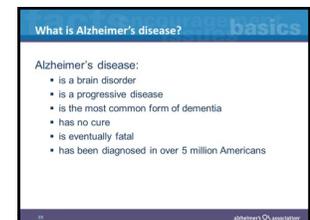
Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- Laura discovered that what many people think about when they hear the words “Alzheimer's disease” may be very different from reality.
- Some of the facts about Alzheimer's may surprise you and may change some of your own misconceptions about the disease.

### **Slide 24**

Alzheimer's is a disease of the brain that causes problems with memory, thinking and behavior. It is not a normal part of aging. Although symptoms can vary widely, the first problem people typically notice is forgetfulness severe enough to affect their ability to function at home or at work, or to enjoy lifelong hobbies.

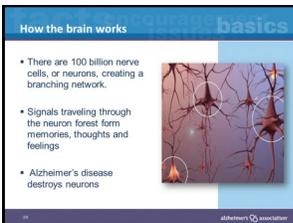


Alzheimer's disease is a brain disorder named for German physician Alois Alzheimer, who first described it in 1906. Scientists have learned a great deal about Alzheimer's disease in the century since Dr. Alzheimer first drew attention to it.

Today we know that:

**Alzheimer's disease is a progressive and fatal brain disease.** Alzheimer's destroys brain cells, causing memory loss and problems with thinking and behavior severe enough to affect work, lifelong hobbies or social life. Alzheimer's gets worse over time, and it is fatal. Today it is the sixth-leading cause of death in the United States.

Although Alzheimer's disease has no current cure, treatments for symptoms, combined with the right services and support, can make life better for the millions of Americans living with Alzheimer's. There is an accelerating worldwide effort under way to find better ways to treat the disease, delay its onset or prevent it from developing.



### Slide 25

To understand how Alzheimer's disease affects our brains, let's look at how the brain works. The brain has approximately 100 billion nerve cells, which are called neurons. Each neuron connects to many others to form communication networks. In addition to neurons, the brain includes cells specialized to support and nourish it.

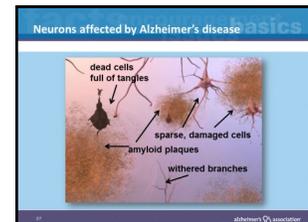
Groups of neurons have special jobs. Some are involved in thinking, learning and memory. Others help us see, hear and smell. Still others tell our muscles when to move. To do their work, brain cells operate like tiny factories. They receive supplies, generate energy, construct equipment and get rid of waste. Cells also process and store information

and communicate with other cells. Keeping everything running requires coordination, as well as large amounts of fuel and oxygen.

Scientists believe that Alzheimer's disease prevents parts of the cell's "factory" from running well. They are not sure where the trouble starts. But just like a real factory, backups and breakdowns in one system cause problems in other areas. As damage spreads, cells lose their ability to do their jobs and eventually die.

### Slide 26

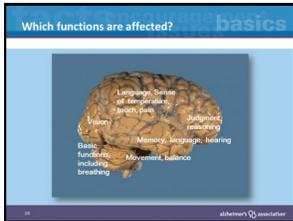
Two abnormal structures called plaques and tangles are prime suspects in damaging and killing nerve cells. In this picture, the plaques and the tangles are pointed out. The damaged nerve cells are also shown. Plaques and tangles were among the abnormalities that Dr. Alois Alzheimer saw in the brain of Auguste D., considered to be the first patient diagnosed with Alzheimer's disease.



**Plaques** build up between nerve cells. They contain deposits of a protein fragment called beta-amyloid (BAY-tuh AM-uh-loyd).

**Tangles** form inside dying cells. Tangles are twisted fibers of another protein called tau (rhymes with "wow"), which assist in the transport of materials that nourish and supply the neurons. When tau collapses, the neurons fall apart and disintegrate. Though most people develop some plaques and tangles as they age, those with Alzheimer's tend to develop far more. The plaques and tangles tend to form in a predictable pattern, beginning in areas important in learning and memory and then spreading to other regions.

Scientists are not absolutely sure what role plaques and tangles play in Alzheimer's disease. Most experts believe they somehow block communication among nerve cells and disrupt activities that cells need to survive.



## **Slide 27**

In the earliest stages, before symptoms can be detected with current tests, plaques and tangles begin to form in brain areas involved in learning and memory, and in thinking and planning. The destruction of brain cells caused by Alzheimer's systematically moves through the brain, damages sections that control memory and language first (the temporal lobe), then begins to destroy the hippocampus, which is a part of the temporal lobe. As the disease progresses, it continues to destroy neurons in the regions of the brain that control other functions as well. Multiple regions can be affected simultaneously.

Plaques and tangles spread to areas involved in speaking and understanding speech, and in the sense of where your body is in relation to objects around you. As Alzheimer's progresses, individuals may experience changes in personality and behavior, and have trouble recognizing friends and family members. It then moves on to affecting judgment and movement (the frontal lobe), then visual processing (the occipital lobe) and movement, orientation, recognition and perception of stimuli (the parietal lobe).

In advanced Alzheimer's disease, most of the cerebral cortex (which contains all of the lobes) is seriously damaged. Individuals lose their ability to communicate, to recognize loved ones and to care for themselves.

In the final stages, the section of the brain controlling our most basic functions (the brain stem), like breathing and swallowing, is damaged.

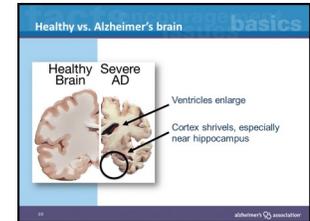
Alzheimer's disease can last anywhere from 3-20 years from onset, and the average life expectancy after onset of symptoms is 4-8 years. \*\*

The length of time that the disease lasts depends in part on age at diagnosis and whether a person has other health conditions.

\*\* Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures

### Slide 28

Here is a comparison view of how massive cell loss changes the whole brain in advanced Alzheimer's disease. Notice the big difference in size between the two brains. What you are seeing is atrophy, or shrinkage, due to cell death in the late stages of Alzheimer's disease.



On the left is a typical adult brain. In the Alzheimer brain, on the right, the cortex shrinks and shrivels up as the result of damage to the neurons, damaging areas involved in thinking, planning and remembering.

Shrinkage is especially severe in the hippocampus, an area of the brain that plays a key role in formation of new memories and is sometimes known as the “memory bank.” You can also see the ventricles pointed out in this slide. These fluid-filled spaces within the brain grow larger as the disease progresses, neurons die, and the brain rids itself of dead tissue. These areas are no longer able to do the jobs they once did, resulting in loss of cognitive function.

### Slides 29 and 30

#### **Film Clip Intro:**

In this video clip, Kitty talks about seeing changes in her husband Bill that had to do with problems with the formation of new memories in the brain.

#### **View film clip**



**Presenter's note:**

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- Kitty's example of this process of memory formation being altered in her husband, Bill, demonstrates how profound this effect can be.
- She says that the lack of sleep caused him to lost the previous day. There is evidence that suggests a connection between sleep and memory storage, and this effect may be more pronounced in people with Alzheimer's disease. The research on this topic is continuing to emerge.



**Slide 31**

While scientists know Alzheimer's disease involves progressive brain cell failure, they have not yet identified any single reason why cells fail. However, they have identified certain risk factors that increase the likelihood of developing Alzheimer's.



**Slide 32**

**Age**

The greatest known risk factor for Alzheimer's is increasing age. Most individuals with the disease are 65 or older. The likelihood of developing Alzheimer's doubles about every five years after age 65. After age 85, the risk reaches nearly 32 percent. \*\*

\*\* Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures

### **Gender**

More women than men have Alzheimer's disease and other dementias. Almost two-thirds of Americans with Alzheimer's are women, and among people age 71 and older, 16 percent of women have Alzheimer's disease and other dementias compared with 11 percent of men. But the reasons for this are not entirely clear.

The most commonly held view has been that the difference is due to the fact that women tend to live longer than men and older age is the greatest risk factor. New research suggests that risk could be higher for women due to biological or genetic variations, or even different life experiences related to education and occupational choices. More research will need to be done to clarify the causes of this gender difference.

### **Race and Ethnicity**

A review of many studies conducted by an expert panel concluded that older African-Americans are about twice as likely to have Alzheimer's and other dementias as older whites. The rate for older Hispanics is about one and a half times the rate for older whites. These differences appear to be primarily related to health, lifestyle and socioeconomic risk factors across racial and ethnic groups.

### **Down syndrome**

Individuals with Down syndrome develop the pathological features and symptoms of Alzheimer's disease in middle age or older adulthood at a much higher rate than the general population. Individuals with Down syndrome often, but not always, develop cognitive decline as they age, usually beginning in their 40s. This can make it difficult to differentiate between Alzheimer's disease and cognitive decline in aging people with Down syndrome.

### **Family history**

Another risk factor is family history. Research has shown that those who have a parent, brother, sister or child with Alzheimer's are at a higher risk to develop Alzheimer's. The risk further increases if more than one family member has the

illness. When diseases tend to run in families, either heredity (genetics) or environmental factors or both may play a role.

## **Genetics (heredity)**

Scientists know genes are involved in Alzheimer's. There are two categories of genes that can play a role in determining whether a person develops a disease. One gene increases the risk of developing Alzheimer's. Another much more rare situation is one in which the genetic structure is deterministic, meaning if you have that set of genes, you **have a 95% chance of developing** Alzheimer's. There are only a few hundred cases like this in the world.

The two categories of genes that play a role in Alzheimer's disease are:

1. Risk genes that increase the likelihood of developing a disease, but do not guarantee it will happen. Scientists have so far identified one Alzheimer risk gene called apolipoprotein E-e4 (APOE-e4). APOE-e4 is one of three common forms of the APOE gene; the others are APOE-e2 and APOE-e3. APOE provides the blueprint for one of the proteins that carries cholesterol in the bloodstream.

Everyone inherits a copy of some form of APOE from each parent. Those who inherit one copy of APOE-e4 have an increased risk of developing Alzheimer's. Those who inherit two copies have an even higher risk, but not a certainty. Scientists do not yet know how APOE-e4 raises risk. In addition to raising risk, APOE-e4 may tend to make symptoms appear at a younger age than usual. Experts believe there may be as many as a dozen other Alzheimer risk genes in addition to APOE-e4.

The other category of gene is:

2. Deterministic genes, which directly cause a disease, guaranteeing that anyone who inherits them will develop the disorder. Scientists have found rare genes that directly cause Alzheimer's in only a few hundred extended families worldwide.

When Alzheimer’s disease is caused by deterministic genes, it is called “familial Alzheimer’s disease” or “autosomal dominant Alzheimer’s disease” and many family members in multiple generations are affected. True familial Alzheimer’s accounts for less than 1 percent of cases.

Genetic tests are available for both APOE-e4 and the rare genes that directly cause Alzheimer’s. However, health professionals do not currently recommend routine genetic testing for Alzheimer’s disease. Testing for APOE-e4 is sometimes included as a part of research studies.

**Presenter’s note:**

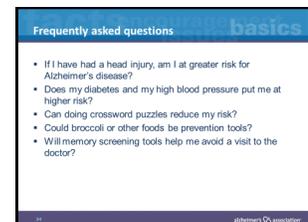
*Refer interested attendees to the Genetics Fact Sheet and other risk factor material.*

**Slide 33**

**Head injury:** There appears to be a strong link between serious or repeated head injury and future risk of Alzheimer’s. People can reduce their risk of developing Alzheimer’s disease by protecting their heads, so buckle your seat belts, wear a helmet when participating in sports and “fall-proof” your home.

**Heart-brain connection:** Some of the strongest evidence links brain health to heart health. Your brain is nourished by one of your body’s richest networks of blood vessels. Every heartbeat pumps about 20 to 25 percent of your blood through the arteries to your head, where brain cells use at least 20 percent of the food and oxygen your blood carries.

The risk of developing Alzheimer’s or vascular dementia appears to be increased by many conditions that damage the heart or blood vessels. These include high blood pressure, heart disease, stroke, diabetes and high cholesterol. Because certain ethnic groups, such as African-Americans and Hispanics, have a higher rate of developing these conditions,



particular attention needs to be paid to diet, physical activity, and medical care in order to reduce the chance of developing vascular problems. Work with your doctor to monitor your heart health and treat any problems that arise.

**General healthy aging:** Other lines of evidence suggest that strategies for overall healthy aging may help keep the brain healthy, and may even offer some protection against developing Alzheimer's or related diseases. Try to keep your weight within recommended guidelines and eat a healthy diet, avoid tobacco and excess alcohol, stay socially connected, and exercise both your body and mind. There is no magic bullet like broccoli or crosswords that is guaranteed to prevent Alzheimer's disease. The goal is overall health, and that includes eating the right kinds of food, engaging in an active social life, and staying mentally active by learning new and challenging things. Though scientists have not yet discovered anything to prevent you from getting Alzheimer's, these things may reduce your risk.

**Memory screening tools** are found in many health fairs, and can even sometimes be purchased online. If you have a question about how you or someone you care about is functioning with regard to memory or thinking, the Alzheimer's Association recommends prompt and thorough evaluation by a doctor. It is important to identify the actual cause of the concern or symptom in order for the person to receive proper care and treatment. One reason for people who suspect dementia to get a diagnosis is so the physician can look for causes of cognitive decline, other than Alzheimer's disease, that may be treatable or reversible. But another reason is so that a potentially life-threatening condition can be diagnosed and treated, and the symptoms reduced or eliminated.

When it comes to prevention of Alzheimer's disease, the best evidence so far points to these risk factors:

- Physical inactivity.



The first step in following up on symptoms is finding a doctor with whom you feel comfortable. People who have pursued a diagnosis report that they are most likely to be satisfied by seeing someone who:

- Is well informed about Alzheimer's disease.
- Has a great deal of experience with diagnosing people with memory problems.
- Is comfortable with age-related concerns.

In some cases, the primary care doctor may refer a patient to one of the following specialists:

- A **neurologist**, who specializes in diseases of the brain and nervous system.
- A **psychiatrist**, who specializes in disorders that affect mood or the way the mind works.
- A **neuropsychologist** with advanced training in testing memory, concentration, problem solving, language and other mental functions.

Another option is to contact an Alzheimer's disease center (ADC) at major medical institutions nationwide. There are about 30 of these centers in the United States, funded by the National Institute on Aging. Many centers offer patients and families:

- Diagnosis and medical management information about the disease.
- Services and resources.
- Opportunities for volunteers to participate in drug trials and other clinical research projects.
- Support groups and other special programs for volunteers and their families.

Someone with symptoms may hesitate to schedule a doctor's appointment due to Alzheimer's disease-related stigma, fear or denial. Rather than confronting the resistance head on, one solution for families may be to accompany the person to an appointment and speak with the doctor privately about what they are noticing. Another solution would be for families contact the doctor either through phone call or letter, describing the changes and symptoms they see at home. Both of these

strategies may encourage the doctor to do a thorough assessment and provide the appropriate interventions. If families continue to have difficulty pursuing a diagnosis, they can contact the local chapter to speak with a care consultant about other strategies and ideas.

**Presenter's note:**

*This is a good spot to mention the chapter's resource listing of diagnostic centers and local hospitals.*

**Slide 36**

Effective communication with your doctor is important for you and your family when you are seeking a diagnosis for memory or other thinking problems. It is important to ask questions, be prepared to answer questions and be as honest as possible.



Questions to ask about testing:

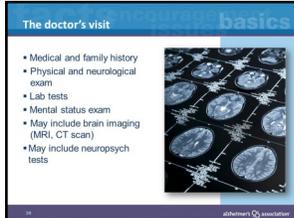
- What tests will be performed?
- What does each test involve?
- How long will the tests take?
- How long will it take to learn results?

Some items you should bring to your visit include:

- A list of symptoms, when they began and how frequently they occur, documented in the form of a journal or the use of care logs.
- A list of past and current medical problems.
- A list of all current medications, herbal remedies, and dietary supplements.
- At least one close family member or friend who can help describe your symptoms and help listen to what the doctor will tell you.

**Presenter's note:**

You may want to refer to and hand out *Preparing for Your Doctor's Visit* checklists, care logs, etc., at this point in the presentation.



### Slide 37

Because there is no single test for Alzheimer's, diagnosis usually involves a thorough medical evaluation which includes: **Medical history**, in which information about current mental or physical conditions, prescription and nonprescription medication use, and family health history is collected.

1. **Mental status evaluation** to assess sense of time and place; ability to remember, understand and communicate; and ability to do simple math problems.  
**A series of evaluations** that test memory, reasoning, visual-motor coordination and language skills.
2. **A physical examination**, which includes:
  - The evaluation of the person's nutritional status, blood pressure and pulse.
  - An examination that tests sensation, balance and other functions of the nervous system.
  - A brain scan to detect other causes of dementia such as stroke.
  - Laboratory tests, such as blood and urine tests, to provide additional information about problems other than Alzheimer's that may be causing dementia.
3. **A psychiatric evaluation**, which provides an assessment of mood and other emotional factors that could cause dementia-like symptoms or may accompany Alzheimer's disease.
4. **Interviews with a spouse, partner or close family member or friend** of the person suspected of dementia -- the doctor may want to talk with someone close to the person suspected of dementia to gather additional information about symptoms. The person with the disease may not realize he or she is exhibiting symptoms. These interviews will provide the physician with further documentation that will help in a diagnosis.

5. **An MRI or another type of brain imaging tool** is typically done to assist with making a diagnosis for a number of reasons. It will show whether the symptoms may be due to another cause, such as strokes or tumors, which would require intervention. In addition, the doctor will look at the degree of brain shrinkage. Some brain shrinkage is typical of aging, but shrinkage that surpasses this typical degree will be another factor for the doctor to take into account when diagnosing.

If the physician seen for the diagnostic assessment has not offered a complete evaluation including these tests, it's important to follow up. The next step is to ask for additional tests to be run by the physician, or ask for a referral to a specialist to complete them. Only with a complete and thorough diagnostic process can everyone involved know what they're dealing with and how to address it.

### Slide 38

Once testing is complete, the doctor will review results and share conclusions. The family should be part of this process and work with the doctor to make sure they are informed. A diagnosis of Alzheimer's disease reflects a doctor's best judgment about the cause of a person's symptoms.

The doctor should explain:

- Why the diagnosis is Alzheimer's.
- **Where the person is in the course of the disease.**
- What to expect in the future.



### Slide 39

Once the diagnosis of Alzheimer's disease is made, emotions run high. There are a lot of feelings that come up very suddenly and it's natural to feel overwhelmed. It is possible, though, to take control and channel some of those emotions into seeking



support and education and to start planning for the future. Grief often plays a role in some of the emotions caregivers may be feeling. Sometimes people do not recognize that the frustration or annoyance they are experiencing toward the person with dementia is really grief over the everyday losses of the disease. Some people who have been searching for a diagnosis for a period of time **feel a sense of relief** when they finally get a definitive reason for their cognitive decline.

**Presenter's note:**

*The conversation can get very personal and involved when emotions are being discussed. Some in the audience may want to ask questions or vent about things that are specific to their situations. These issues are important to them and should get addressed, but may not be best dealt with in a public dementia education program.*

*When you feel that the discussion has moved past the point where most people can relate to the audience member, it's a good idea to refer them to chapter services, and to the Association's national Helpline (800.272.3900) for 24/7 support.*

*The Caregiver Stress Check at [alz.org](http://alz.org) can be a helpful tool here as well.*



**Slide 40**

In each individual, the course of Alzheimer's disease is different. Some people with the disease become more agitated, while others get more calm and even-tempered. The most pronounced changes early on in the disease may be about mood, memory or getting lost. But beyond the specifics of how each person functions with Alzheimer's disease, there are some general statements that can be made about how the disease progresses and what can be expected at each of these stages.

Sometimes, these stages are numbered one through seven, with Stage One being no impairment at all, and Stage Seven being the very end stage of the disease, which ultimately ends with death. There are detailed descriptions of these stages, and people sometimes try to fit what they see into one of these stages to help them understand what to expect in the person about whom they are concerned.

There are other ways to categorize the progression of Alzheimer's disease. One common way to describe the progression, and the one we'll use today, is to talk about three stages of Alzheimer's disease: early stage (or mild Alzheimer's), middle stage (or moderate Alzheimer's) and late stage (or severe Alzheimer's). It's important to keep in mind that each individual's progression through the disease is different, and people may appear to be in a number of different stages at any given time. Which stage the person is in matters far less than understanding how the person is functioning and how to make accommodations for his or her needs. As the disease progresses from one stage to the next, attention will need to be paid to keeping the person safe and to retaining a sense of self.

Keeping in mind that each person's experience will differ, let's take a quick look at the early, middle and late stages of the disease.

Recent memory loss is the hallmark of early-stage Alzheimer's disease. The person in the early stages of the disease may have difficulty managing money, driving, or handling social conversations as he or she once had. These behaviors represent a shift from the person's previous state, and the changes are noticeable to those closest to them.

The middle stage involve greater difficulty with written and spoken language. People in this stage may get lost in familiar settings, and may have problems with keeping track of personal items, which results in accusing others of taking things from them. They may become confused about the day of the week or the season, causing them to dress in clothing that

is inappropriate for the weather. They often require assistance with managing personal grooming in the middle stages of the disease as well.

In the late stage of Alzheimer’s disease, both short-term and long-term memory are affected. Language is reduced to basic words or sounds, and communication with the person is carried out using short sentences and gestures. Ultimately, the person in the late stages of the disease becomes completely dependent on caregivers to take care of all tasks, and care must be provided around the clock.

Throughout all of these stages, it is the job of the care partner or caregiver to help the person retain his or her sense of self and dignity. Even at the end of life, the person with Alzheimer’s disease may feel comforted by touch, sound and taste. Providing those sensations allows the person to maintain a sense of self, connect with others and continue to relate to his or her surroundings.

**Presenter’s note:**

*The Alzheimer’s Association’s brochure, “Basics of Alzheimer’s Disease: What It Is and What You Can Do”, provides more information about the stages and currently available treatments. It is helpful to provide your audience with copies of this brochure.*



**Slides 41 and 42**

In this next video, Dr. Monica Parker, a geriatrician with Emory University, talks about the need to make plans for the future early in the disease process.

**View film clip**

**Presenter's note:**

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

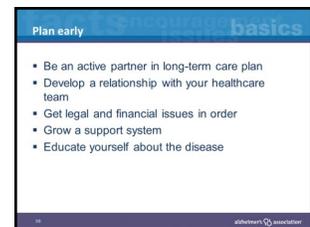
- Dr. Parker stresses the need for making plans for parents before those arrangements become urgent needs.
- We need to be sure that we do the same for ourselves and for others closest to us.

**Slide 43**

In the early stages, it's important for a person with Alzheimer's disease to make decisions with family members about future care.

This helps everyone in a couple of important ways:

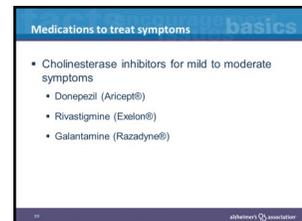
- It allows arrangements to be made to provide for the person with the disease before they are urgently needed and other issues may force decisions to be rushed.
- It also allows the person living with the disease to make plans that fit with his or her preferences and to maximize control over the future.



**Slide 44**

Currently, there is no cure for Alzheimer's and no way to stop the underlying death of brain cells. But drugs and non-drug treatments may help with both cognitive and behavioral symptoms.

Two types of drugs are currently approved by the U.S. Food and Drug Administration (FDA) to treat cognitive symptoms of Alzheimer's disease.



The first type, cholinesterase (*KOH-luh-NES-ter-ays*) inhibitors, is designed to prevent the breakdown of acetylcholine (*a-SEA-til-KOHlean*), a chemical messenger important for memory and learning. By keeping levels of acetylcholine high, these drugs support communication among nerve cells. They delay worsening of symptoms for six to 12 months for about half of the people who take them.

Three cholinesterase inhibitors are commonly used to treat Alzheimer's:

- Donepezil (Aricept®), approved in 1996, now used to treat all degrees of Alzheimer's (mild, moderate and severe).
- Rivastigmine (Exelon®), approved in 2000 for mild to moderate Alzheimer's.
- Galantamine (Razadyne®), approved in 2001 for mild to moderate Alzheimer's.

In 2014, a medication combining Namenda and Aricept was released. Called, Namzaric, this medication is designed for people with moderate to severe Alzheimer's-related dementia who are already on stable doses of Namenda and Aricept.



### Slide 45

The second type of drug works by regulating the activity of glutamate, a different messenger chemical involved in information processing:

- Memantine (Namenda®), approved in 2003.

Memantine is the only currently available drug in this class, and may temporarily delay the worsening of symptoms for some people.



### Slides 46 and 47

#### **Film Clip Intro:**

Here is Dr. Peterson to describe how medications can be helpful.

**View film clip**

**Presenter's note:**

Please insert your own 1-2 sentence comment about the video clip here.

Important points from the film:

- Dr. Peterson makes the point that the medications that are currently available will not change the outcome of the disease. It will still progress.
- Medications can be useful during the course of the disease, with positive short-term effects on behavior and cognition.

**Slide 48**

Over the last 15 years, scientists have made enormous strides in understanding how Alzheimer's disease affects the brain. Many recent insights point toward promising new strategies for treatment, prevention and diagnosis.

When it comes to the most current thinking about treatments for Alzheimer's disease, researchers and experts currently don't expect a "magic bullet" that will do the job. Instead, they are looking at a combination of drugs that will function more like an AIDS or chemotherapy "cocktail." But in order for any drug to reach the market, it has to undergo a rigorous period of testing.

First, there is carefully documented laboratory work, which is followed by animal studies. Once the medication has been shown to be safe and effective there, new treatments must undergo clinical studies (testing in human volunteers, also called "clinical trials").

A broad range of drugs are in clinical trials now. These drugs impact biological processes associated with Alzheimer's. Involvement with a clinical trial can have a number of benefits:



- Contributing to the body of knowledge that will lead to eventual treatments and cures.
- Accessing the latest medications.
- Receiving a high standard of care.

Clinical studies are the engine that powers medical progress. Scientists work constantly to find better ways to treat diseases. Improved treatments can never become a reality without testing in human volunteers. No one ever chooses to become ill, but anyone can consider helping to advance knowledge about an illness affecting them or someone close to them.

There are many clinical studies now recruiting participants with and without Alzheimer’s disease to find better ways to treat the disease. No treatment being investigated can advance to the stage of clinical testing unless there is strong evidence indicating it will be as good as, or better than, the therapies that are currently available.

All participants receive regular care related to the study and opportunities to talk with study staff. Research shows that people involved in studies tend to do somewhat better than people in a similar stage of their disease who are not enrolled, regardless of whether the experimental treatment works. Scientists believe this advantage may be due to the general high quality of care provided during clinical studies.

Find out more about clinical trials and how to get involved by visiting the Alzheimer’s Association Web site at [www.alz.org](http://www.alz.org).



**Slide 49**

The Alzheimer’s Association has many programs and services to help you and your family. There are also a lot of ways to get involved.

## Slide 50

No matter whether you want information or support; whether you have questions about memory loss or a dementia of any kind; or whether you are a professional, a researcher, a caregiver or a person diagnosed with Alzheimer's disease or another form of dementia, the Alzheimer's Association has resources for you and is available to help.

In addition to our live programs, we have a rich website at [alz.org](http://alz.org). Visit our website to get tips about finding and providing care, read about the latest research, and find the tools for your wellbeing. Spend some time exploring all we have to offer for you at [alz.org](http://alz.org).

One of the online tools that you'll find on our website is Alzheimer's Navigator. We can help you map out a plan to approach Alzheimer's by visiting the Web page at [alzheimersnavigator.org](http://alzheimersnavigator.org). Alzheimer's Navigator helps guide you to answers by creating a personalized action plan containing information, support and local resources. You can then share your plan with your friends and family, linking them to the materials customized for your situation.

By visiting our Community Resource Finder online tool at [communityresourcefinder.org](http://communityresourcefinder.org), you can search for local community living services, day programs, medical resources and more. Whether you are in the area or across the country, you can find services to help someone living with dementia and make the contacts you all need to ensure safety and comfort.

A rich supplement to our local supportive programs is ALZConnected, our online message boards with over 50,000 members who share their thoughts, questions and ideas with each other 24 hours a day. Whether you are living with dementia or are close to someone who is, you can come on to read or post about your concerns. Let ALZConnected help you



develop plans, find support and discover new coping techniques by connecting with others who are living with dementia or are partners in caring.

Our 24/7 Helpline offers dementia-trained professionals to talk with any time, day or night, every day of the year. Call us at 800.272.3900 when you need information about the disease and meeting its challenge, links to resources or a supportive ear during difficult times. We are here to help.

The Alzheimer's Association has chapters all through the country, where we offer education programs, support groups, and much more. To find a chapter anywhere in the U.S., go to [alz.org/findus](http://alz.org/findus), where you can search by state or zip code. Once on the chapter's web page, you can see what is being offered in that area.

Finally, the Training and Education Center of [alz.org](http://alz.org) is where you can access programs like this one from the convenience of home. Just go to [alz.org/training](http://alz.org/training), and you can find programs and materials that offer the most current information about dementia, treatments and care.

Please contact us and let the Alzheimer's Association partner with you to help ensure your wellbeing.

***Presenter's note:***

*Here is the spot to highlight what you are doing at your chapter, including upcoming programs, events and resources specific to the location of this presentation. Flyers and brochures from your chapter can be placed on the resource table along with the Know the 10 Signs and Principles for a Dignified Diagnosis materials.*

## **Slide 51**

You can use your voice, your motivation, your interest and your skills to help find new treatments and to enhance services for all people affected by dementia.

Clinical trials research studies are being conducted all over the world to find treatments are safe and effective. Clinical trials are the best way for researchers to find new ways to detect, slow, treat and hopefully someday prevent Alzheimer's disease. The Alzheimer's Association's TrialMatch is a free clinical studies matching service that connects individuals with Alzheimer's, caregivers and healthy volunteers to local clinical trials seeking participants. When you join a clinical trial, you have an opportunity to participate in vital research that could change the course of Alzheimer's disease and improve the lives of all those it affects. Visit TrialMatch online at [trialmatch.alz.org](http://trialmatch.alz.org) or call our Helpline at 800.272.3900 to get started making a difference.



The Walk to End Alzheimer's and The Longest Day are opportunities for the local community to join together in the spirit of grassroots advocacy that is central to the mission of the Alzheimer's Association. Forming a team to support a friend or family member is a direct way to show your concern for the person as well as for the cause, and those who live with the impact of these diseases in their lives are tremendously grateful.

We also encourage you to join us in providing education and support programs to families in your area who are living with Alzheimer's and other forms of dementia. Whether you are a person with the disease, a care partner or caregiver, or a professional in the field, you can volunteer to use your knowledge and compassion to have a profound impact on those whose lives are affected by the disease.

### *Presenter's note:*

*This is the time to highlight volunteer activities at your chapter and to circulate recruitment materials.*

You can also join us to speak up for the needs and rights of people with Alzheimer's and their families, and to help persuade state and federal Congress to increase funding for research and programs. Many caregivers and people with the disease find the experience of advocating to be therapeutic, and it puts a human face on complex policy issues for our legislators.

We need you to help us change the course of Alzheimer's disease for everyone affected, and we welcome you to join us in making a difference.



### **Slide 52 and 53**

#### **Film Clip Intro:**

In our final film clip, Betsy describes the importance of building a network for yourself.

#### **View film clip**

#### ***Presenter's note:***

Please insert your own 1-2 sentence comment about the video clip here.

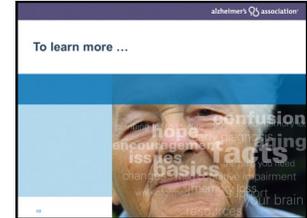
Important points from the film:

- It's important to build your network ahead of time, before you need it.
- You can't do it all and you can't do it alone.
- The Alzheimer's Association is here to help you and can be part of your care community.

# facts encouragement basics

## **Slide 54**

There are many ways to learn more about memory loss, dementia and Alzheimer’s disease. No matter whether you want information or support; whether you have questions about memory loss or a dementia of any kind; or whether you are a professional, a researcher, a caregiver or a person diagnosed with Alzheimer’s disease, the Alzheimer’s Association has resources for you and is available to help. We look forward to hearing from you!



### ***Presenter’s note:***

Here is the spot to highlight the education programs that will go into greater detail about Alzheimer’s disease and caregiver issues.

*Add any final thoughts here.*

We have xx minutes left for any questions you might have.

### ***Presenter’s note:***

*Take questions from the audience and remind them of upcoming programs and events, as well as the materials you have available. Remind them to fill out the evaluation sheets and turn them in to you.*

## **Slide 55**

(No text)

