An Education Program by the Alzheimer's Association

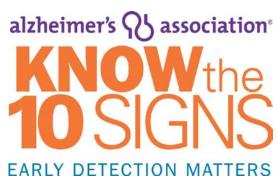
know the 10 signs

early detection matters



Presented by:





Original Edit: 12/2015



Family Studies and Human Services

343 Justin Hall 1324 Lovers Lane Manhattan, KS 66506-1400

Dear Presenter,

Thank you for your consideration toward presenting the program, "Know The 10 Signs: Early Detection Matters". As you're well aware, the aging population of Kansas is exponentially growing, and will continue to do so over the next few decades. Along with that will come unique opportunities as well as challenges, one of which is Alzheimer's disease. Everyone with a brain is at risk for Alzheimer's. One in three seniors will die with Alzheimer's disease or another form of dementia, and it is the sixth leading cause of death in the United States. Currently, Alzheimer's cannot be prevented, cured, or slowed and will cost our nation \$226 billion in 2015. In Kansas, 51,000 people (or 12%) age 65 or older currently have Alzheimer's disease, a rate which is expected to rise to 22% over the next 10 years. In addition to sufferers, there are 150,000 Alzheimer's caregivers in Kansas, which results in 171 million hours of unpaid care valued at \$2.1 billion. The concern is clear: Alzheimer's is a terrifying and timely issue affecting over 100,000 Kansans every day.

There are strides we can take, and as the program title states, early detection matters. Through early detection, an individual can receive the maximum benefit from available treatments, as well as have more time during which to embrace life and plan for their, and their caregivers', future. The purpose of this program is to enable the public with knowledge on the differences between age-related memory loss and dementia, and what to do if they have signs of Alzheimer's disease. It is the goal that this knowledge will ultimately encourage early detection, early diagnosis, and early intervention.

It is my honor to have partnered with the Alzheimer's Association - Heart of America Chapter to bring this evidence-based program to K-State Research and Extension. It is my hope that this knowledge can elicit greater understanding and compassion among and toward those with Alzheimer's disease, in addition to promoting early detection, diagnosis, and intervention.

As always, if you have questions or need further clarification, please contact me.

Here's to brain health and Alzheimer's awareness.

Erin Yelland, Ph.D., CFLE

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Kansas State University, County Extension Councils, Extension Districts, and U.S. Department of Agriculture Cooperating.

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The Basics

Program length: 1 hour + 30 minutes for the optional brain tour

Program materials: Know the 10 Signs PowerPoint slideshow, Alzheimer's Association's "Want to Know More?" sheet, "How Much Do You Know?" worksheet, participant handouts (fact sheet, PowerPoint printout, brain tour print out), and evaluation. Don't forget to order magnets and a 3-panel poster from the KSRE bookstore!

Evaluation: The evaluation will be given at the end of the program.

Reporting: The Alzheimer's Association's "Want to Know More?" form and the evaluations HAVE TO BE REPORTED TO THE ALZHEIMER'S ASSOCIATION! To do this, send everything to Dr. Erin Yelland via one of the following methods:

- 1. scan the documents and e-mail them to erinyelland@ksu.edu
- 2. mail the documents to: Erin Yelland, 343 Justin Hall, 1324 Lovers Lane, Manhattan, KS 66506

Dr. Yelland will then log the information, report to KPICS, and forward everything on to the Alzheimer's Association. IT IS RECOMMENDED THAT YOU COPY THE EVALUATIONS FOR YOUR OWN LOCAL UNIT REPORTING PURPOSES.

Overview

purpose and goals

There is reluctance within the general public to visit a doctor once signs or symptoms of dementia are noticed. Both fear and stigma have a role in this reluctance, which results in a delay in getting treatment that may help alleviate symptoms. In a concrete example of the impact of Alzheimer stigma, a 2006 Harris Interactive Poll of 539 caregivers who were currently caring for a parent or spouse with Alzheimer's found:

- 1. Patients typically had Alzheimer symptoms for two years and saw two doctors before getting diagnosed with Alzheimer's.
- 2. Caregivers' concern about Alzheimer stigma delayed diagnosis by up to six years.

Similarly, in a national poll commissioned by the Alzheimer Society of Canada, Ipsos-Reid polled 1,000 Canadians in 2002 and found 81 percent of Canadians nationwide responded affirmatively to the question: "I think people would look at me or treat me differently if I were diagnosed with Alzheimer's disease."

The goal of this program is to provide compelling information about Alzheimer's disease, and moving testimony from families living with the disease, to encourage early detection, early diagnosis and early intervention.

The purpose of this workshop is to provide the general public with a greater understanding of the difference between age-related memory loss and dementia, and what to do if they have signs of Alzheimer's disease.

By the end of the presentation:

- Participants will be able to identify the 10 warning signs of Alzheimer's disease and what to do next if they are experiencing signs of Alzheimer's.
- Participants will understand what is involved in getting a diagnosis.
- Participants will be able to identify the risks of Alzheimer's, including connections to other conditions.
- Participants will understand the benefits of early detection.

audience

This presentation was designed for an audience interested in learning more about the early detection of Alzheimer's disease. It is for anyone experiencing signs of memory loss or other unaccountable changes in behavior that makes them think that something is different or wrong with their health. Other audience members may attend because they are worried about a family member or friend. Members of the audience may believe they have symptoms and want to learn more. Others may not be worried at all.

Most of the time, this workshop will be delivered in a general community setting or in a setting designed for seniors. It is designed for those who are not diagnosed but may be worried about signs they see in themselves or a family member or friend, or those who are generally curious about the disease.

They may be somewhat frightened about the issue of memory loss in themselves or a loved one. The program is designed to address their fears with information and encouragement, and focuses on the reasons to visit a doctor to get assessed. The video vignettes inserted throughout the program show people in the early stage of the dis- ease talking about stigma, diagnosis, intervention and adjustment, and will help dispel some of the fears of addressing symptoms. Each of the videos 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 should auto-launch when the presenter advances to this slide, either on the laptop itself or by using a remote control. If the video does not automatically start playing, press the right arrow key or space bar once.

instructions

Session Delivery

The content of the PowerPoint presentation has seven sections:

- 1. Introduction
- 2. Alzheimer's disease vs. typical aging
 - *Optional: The Brain Tour
- 3. Risk factors for Alzheimer's: How the risks affect you
- 4. The 10 warning signs
- 5. Diagnosis: Earlier is better
- 6. If you do get a diagnosis of dementia...
- 7. You are not alone: Resources to help

*You will have the option of including the virtual brain tour (www.alz.org/braintour) after section 2 (Alzheimer's Disease vs. Typical Aging). Please see the Brain Tour section for more information.

Delivery Methods

Your expertise and personality are two keys to making this presentation a success. Although we have laid out content and script, we encourage you to add personal touches by offering your own case examples and insights.

- Familiarize yourself with the program prior to the presentation. Practice presenting the workshop so that you are comfortable with the content and using the interactive components, including video.
- Familiarize yourself with the group that you are training. Are they seniors in the community, in a facility, or a combination? Are they younger than 65 or more likely to be caregivers? Are they in a workplace?

- Make one or two copies (depending on class size) of:
 - The "Want to Know More?" form
- Make enough copies for your group of:
 - The fact sheet: Know the 10 Signs: Early Detection Matters
 - The PowerPoint handout
 - The Brain Tour handout (if applicable)
 - The worksheet: How Much Do You Know?
 - The evaluation
- Arrive early to make sure that the presentation room is set up properly, your technology is connected and working and all your materials are arranged and available.

How Much Do You Know? Worksheet

This worksheet will be handed out to the attendees as they arrive, to allow time for completion before the presentation begins. Please follow the presenter instructions at the top of the worksheet. Keep in mind time will be needed after the slide presentation is complete to facilitate a discussion regarding their initial thoughts about Alzheimer's and what they have learned during the workshop.

Notes

A Little about Alzheimer's

Alzheimer's Disease

FACT SHEET

Alzheimer's Disease — Get the Facts

- Changes in the Brain
- Signs and Symptoms
- What Causes Alzheimer's
- Diagnosis
- Treatment
- Participating in Clinical Trials
- Support for Families and Caregivers
- For More Information

lzheimer's disease is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks. In most people with Alzheimer's, symptoms first appear in their mid-60s. Estimates vary, but experts suggest that more than 5 million Americans may have Alzheimer's.

Alzheimer's disease is currently ranked as the sixth leading cause of death in the United States, but recent estimates indicate that the disorder may rank third, just behind heart disease and cancer, as a cause of death for older people.

Alzheimer's is the most common cause of dementia among older adults. Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of daily living.

The causes of dementia can vary, depending on the types of brain changes that may be taking place. Other dementias include Lewy body dementia, frontotemporal disorders, and vascular dementia. It is common for people to have mixed dementia—a combination of two or more disorders, at least one of which is dementia. For example, some people have both Alzheimer's disease and vascular dementia.

Alzheimer's disease is named after Dr. Alois Alzheimer. In 1906, Dr. Alzheimer noticed changes in the brain tissue of a woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems, and

unpredictable behavior. After she died, he examined her brain and found many abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary, or tau, tangles).

These plaques and tangles in the brain are still considered some of the main features of Alzheimer's disease. Another feature is the loss of connections between nerve cells (neurons) in the brain. Neurons transmit messages between different parts of the brain, and from the brain to muscles and organs in the body.

Changes in the Brain

Scientists continue to unravel the complex brain changes involved in the onset and progression of Alzheimer's disease. It seems likely that damage to the brain starts a decade or more before memory and other cognitive problems appear. During this preclinical stage of Alzheimer's disease, people seem to be symptom-free, but toxic changes are taking place in the brain. Abnormal deposits of proteins form amyloid plaques and tau tangles throughout the brain, and once-healthy neurons stop functioning, lose connections with other neurons, and die.

The damage initially appears to take place in the hippocampus, the part of the brain essential in forming memories. As more neurons die, additional parts of the brain are affected, and they begin to shrink. By the final stage of Alzheimer's, damage is widespread, and brain volume has shrunk significantly.

Healthy Brain Severe Alzheimer's Cross sections of the brain show atrophy, or shrinking, of brain tissue caused by Alzheimer's disease.

Signs and Symptoms

Memory problems are typically one of the first signs of cognitive impairment related to Alzheimer's disease. Some people with memory problems have a condition called mild cognitive impairment (MCI). In MCI, people have more memory problems than normal for their age, but their symptoms do not interfere with their everyday lives. Movement difficulties and problems with the sense of smell have also been linked to MCI. Older people with MCI are at greater risk for developing Alzheimer's, but not all of them do. Some may even go back to normal cognition.

The first symptoms of Alzheimer's vary from person to person. For many, decline in non-memory aspects of cognition, such as word-finding, vision/spatial issues, and impaired reasoning or judgment, may signal the very early stages of Alzheimer's disease. Researchers are studying biomarkers (biological signs of disease found in brain images, cerebrospinal

fluid, and blood) to see if they can detect early changes in the brains of people with MCI and in cognitively normal people who may be at greater risk for Alzheimer's disease. Studies indicate that such early detection may be possible, but more research is needed before these techniques can be relied upon to diagnose Alzheimer's disease in everyday medical practice.

Mild Alzheimer's Disease

As Alzheimer's disease progresses, people experience greater memory loss and other cognitive difficulties. Problems can include wandering and getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, and personality and behavior changes. People are often diagnosed at this stage.

Moderate Alzheimer's Disease

In this stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought. Memory loss and confusion grow worse, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out multistep tasks such as getting dressed, or cope with new situations. In addition, people at this stage may have hallucinations, delusions, and paranoia and may behave impulsively.

Severe Alzheimer's Disease

Ultimately, plaques and tangles spread throughout the brain, and brain tissue shrinks significantly. People with severe Alzheimer's cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down.

What Causes Alzheimer's

Scientists don't yet fully understand what causes Alzheimer's disease in most people. In people with early-onset Alzheimer's, a genetic mutation is usually the cause. Late-onset Alzheimer's arises from a complex series of brain changes that occur over decades. The causes probably include a combination of genetic, environmental, and lifestyle factors. The importance of any one of these factors in increasing or decreasing the risk of developing Alzheimer's may differ from person to person.

The Basics of Alzheimer's

Scientists are conducting studies to learn more about plaques, tangles, and other biological features of Alzheimer's disease. Advances in brain imaging techniques allow researchers to see the development and spread of abnormal amyloid and tau proteins in the living brain, as well as changes in brain structure and function. Scientists are also exploring the very earliest steps in the disease process by studying changes in the brain and body fluids that can be detected years before Alzheimer's symptoms appear. Findings from these studies will help in understanding the causes of Alzheimer's and make diagnosis easier.

One of the great mysteries of Alzheimer's disease is why it largely strikes older adults. Research on normal brain aging is shedding light on this question. For example, scientists are learning how age-related changes in the brain may harm neurons and contribute to Alzheimer's damage. These age-related changes include atrophy (shrinking) of certain parts of the brain, inflammation, production of unstable molecules called free radicals, and mitochondrial dysfunction (a breakdown of energy production within a cell).

Genetics

Most people with Alzheimer's have the late-onset form of the disease, in which symptoms become apparent in their mid-60s. The apolipoprotein E (APOE) gene is involved in late-onset Alzheimer's. This gene has several forms. One of them, APOE $\epsilon 4$, increases a person's risk of developing the disease and is also associated with an earlier age of disease onset. However, carrying the APOE $\epsilon 4$ form of the gene does not mean that a person will definitely develop Alzheimer's disease, and some people with no APOE $\epsilon 4$ may also develop the disease.

Also, scientists have identified a number of regions of interest in the genome (an organism's complete set of DNA) that may increase a person's risk for lateonset Alzheimer's to varying degrees.

Early-onset Alzheimer's disease occurs in people age 30 to 60 and represents less than 5 percent of all people with Alzheimer's. Most cases are caused by an inherited change in one of three genes, resulting in a type known as early-onset familial Alzheimer's disease, or FAD. For others, the disease appears to develop without any specific, known

cause, much as it does for people with late-onset disease.

Most people with Down syndrome develop Alzheimer's. This may be because people with Down syndrome have an extra copy of chromosome 21, which contains the gene that generates harmful amyloid.

For more about Alzheimer's genetics research, see the **Alzheimer's Disease Genetics Fact Sheet**, available at www.nia.nih.gov/alzheimers/publication/alzheimers-diseasegenetics-fact-sheet.

Health, Environmental, and Lifestyle Factors

Research suggests that a host of factors beyond genetics may play a role in the development and course of Alzheimer's disease. There is a great deal of interest, for example, in the relationship between cognitive decline and vascular conditions such as heart disease, stroke, and high blood pressure, as well as metabolic conditions such as diabetes and obesity. Ongoing research will help us understand whether and how reducing risk factors for these conditions may also reduce the risk of Alzheimer's.

A nutritious diet, physical activity, social engagement, and mentally stimulating pursuits have all been associated with helping people stay healthy as they age. These factors might also help reduce the risk of cognitive decline and Alzheimer's disease. Clinical trials are testing some of these possibilities.

Diagnosis of Alzheimer's Disease

Doctors use several methods and tools to help determine whether a person who is having memory problems has "possible Alzheimer's dementia" (dementia may be due to another cause) or "probable Alzheimer's dementia" (no other cause for dementia can be found).

To diagnose Alzheimer's, doctors may:

- Ask the person and a family member or friend questions about overall health, past medical problems, ability to carry out daily activities, and changes in behavior and personality
- Conduct tests of memory, problem solving, attention, counting, and language
- Carry out standard medical tests, such as blood and urine tests, to identify other possible causes of the problem
- Perform brain scans, such as computed tomography (CT), magnetic resonance imaging (MRI), or positron emission tomography (PET), to rule out other possible causes for symptoms.

These tests may be repeated to give doctors information about how the person's memory and other cognitive functions are changing over time.

Alzheimer's disease can be *definitively* diagnosed only after death, by linking clinical measures with an examination of brain tissue in an autopsy.

People with memory and thinking concerns should talk to their doctor to find out whether their symptoms are due to Alzheimer's or another cause, such as stroke, tumor, Parkinson's disease, sleep disturbances, side effects of medication, an infection, or a non-Alzheimer's dementia. Some of these conditions may be treatable and possibly reversible.

If the diagnosis is Alzheimer's, beginning treatment early in the disease process may help preserve daily functioning for some time, even though the underlying disease process cannot be stopped or reversed. An early diagnosis also helps families plan for the future. They can take care of financial and legal matters, address potential safety issues, learn about living arrangements, and develop support networks.

In addition, an early diagnosis gives people greater opportunities to participate in clinical trials that are testing possible new treatments for Alzheimer's disease or other research studies.

Treatment of Alzheimer's Disease

Alzheimer's disease is complex, and it is unlikely that any one drug or other intervention will successfully treat it. Current approaches focus on helping people maintain mental function, manage behavioral symptoms, and slow or delay the symptoms of disease. Researchers hope to develop therapies targeting specific genetic, molecular, and cellular mechanisms so that the actual underlying cause of the disease can be stopped or prevented.

Maintaining Mental Function

Several medications are approved by the U.S. Food and Drug Administration to treat symptoms of Alzheimer's. Donepezil (Aricept®), rivastigmine (Exelon®), and galantamine (Razadyne®) are used to treat mild to moderate Alzheimer's (donepezil can be used for severe Alzheimer's as well). Memantine (Namenda®) is used to treat moderate to severe Alzheimer's. These drugs work by regulating neurotransmitters,

Participating in Clinical Trials

Everybody—those with Alzheimer's disease or mild cognitive impairment as well as healthy volunteers with or without a family history of Alzheimer's—may be able to take part in clinical trials and studies. Participants in Alzheimer's clinical research help scientists learn how the brain changes in healthy aging and in Alzheimer's. Currently, at least 70,000 volunteers are needed to participate in more than 150 active clinical trials and studies that are testing ways to understand, diagnose, treat, and prevent Alzheimer's disease.

Volunteering for a clinical trial is one way to help in the fight against Alzheimer's disease. Studies need participants of different ages, sexes, races, and ethnicities to ensure that results are meaningful for many people.

The National Institute on Aging (NIA) at the National Institutes of Health (NIH) leads the Federal Government's research efforts on Alzheimer's. NIA-supported Alzheimer's Disease Centers throughout the United States conduct a wide range of research, including studies of the causes, diagnosis, and management of Alzheimer's. NIA also sponsors the Alzheimer's Disease Cooperative Study (ADCS), a consortium of leading researchers throughout the United States and Canada who conduct clinical trials.

To find out more about Alzheimer's clinical trials and studies:

- Talk to your health care provider about local studies that may be right for you.
- Visit the ADEAR Center website at www.nia.nih.gov/alzheimers/volunteer.
- Contact Alzheimer's disease centers or memory or neurology clinics in your community.
- Search the ADEAR Center clinical trials finder for a trial near you or to sign up for email alerts about new trials: www.nia.nih.gov/alzheimers/clinical-trials.
- Sign up for a registry (such as the Alzheimer's Prevention Registry) or matching service (such as TrialMatch) to be invited to participate in studies.

Learn more in Participating in Alzheimer's Research: For Yourself and Future Generations, at www.nia.nih.gov/alzheimers/publication/participating-alzheimers-research.

the brain chemicals that transmit messages between neurons. They may help maintain thinking, memory, and communication skills, and help with certain behavioral problems. However, these drugs don't change the underlying disease process. They are effective for some but not all people and may help only for a limited time.

Managing Behavior

Common behavioral symptoms of Alzheimer's include sleeplessness, wandering, agitation, anxiety, and aggression. Scientists are learning why these symptoms occur and are studying new treatments—drug and nondrug—to manage them. Research has shown that treating behavioral symptoms can make people with Alzheimer's more comfortable and makes things easier for caregivers.

Looking for New Treatments

Alzheimer's disease research has developed to a point where scientists can look beyond treating symptoms to think about addressing underlying disease processes. In ongoing clinical trials, scientists are developing and testing several possible interventions, including immunization therapy, drug therapies, cognitive training, physical activity, and treatments used for cardiovascular disease and diabetes.

Support for Families and Caregivers

Caring for a person with Alzheimer's disease can have high physical, emotional, and financial costs. The

demands of day-to-day care, changes in family roles, and decisions about placement in a care facility can be difficult. There are several evidencebased approaches and programs that can help, and researchers are continuing to look for new and better ways to support caregivers.

Becoming well-informed about the disease is one important strategy. Programs that teach families about the various stages of Alzheimer's and about ways to deal with difficult behaviors and other caregiving challenges can help.

Good coping skills, a strong support network, and respite care are other ways that help caregivers handle the stress of caring for a loved one with Alzheimer's disease. For example, staying physically active provides physical and emotional benefits.

Some caregivers have found that joining a support group is a critical lifeline. These support groups allow caregivers to find respite, express concerns, share experiences, get tips, and receive emotional comfort. Many organizations sponsor in-person and online support groups, including groups for people with early-stage Alzheimer's and their families.

For more information, see Caring for a Person with Alzheimer's Disease:
Your Easy-to-Use Guide from the National Institute on Aging at
www.nia.nih.gov/alzheimers/publication/
caring-person-alzheimers-disease.

For More Information About Alzheimer's

To get more information about Alzheimer's and learn about support groups and services for people with the disease and their caregivers, contact the following organizations:

Alzheimer's Disease Education and Referral (ADEAR) Center

1-800-438-4380 (toll-free) adear@nia.nih.gov www.nia.nih.gov/alzheimers

The National Institute on Aging's ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer's disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. Visit the ADEAR website to learn more about Alzheimer's and other dementias, find clinical trials, and sign up for email updates.

Alzheimer's Association

1-800-272-3900 (toll-free) 1-866-403-3073 (TTY/toll-free) info@alz.org www.alz.org

Alzheimer's Foundation of America

1-866-232-8484 (toll-free) info@alzfnd.org www.alzfdn.org

Eldercare Locator

 $\begin{array}{c} 1\text{-}800\text{-}677\text{-}1116 \text{ (toll-free)} \\ \text{eldercarelocator@n4a.org} \\ www.eldercare.gov \end{array}$

Family Caregiver Alliance

1-800-445-8106 (toll-free) info@caregiver.org www.caregiver.org

MedlinePlus

www.nlm.nih.gov/medlineplus/alzheimersdisease.html



National Institute on Aging National Institutes of Health NIH...Turning Discovery Into Health® U.S. Department of Health and Human Services





Early Detection and Diagnosis of Alzheimer's

Why is an early Alzheimer's diagnosis important?

Alzheimer's is a degenerative disease that gradually destroys brain cells and is ultimately fatal. In the mild stage, memory loss and confusion begin to affect people's everyday activities. In the moderate and severe stages, the progressive destruction of nerve cells not only causes memory failure, but also changes behavior and personality. Physical abilities – including the ability to walk, sit, and eventually, to swallow – become impaired and communication is difficult. Ultimately, round-the-clock, intensive care becomes necessary.

Receiving a formal diagnosis early in the disease progression enables the best medical care and health outcomes for people with the disease. Even without a way to cure or slow the progression of Alzheimer's, early diagnosis provides individuals and their caregivers with access to available treatments, support services, and the opportunity to enroll in clinical trials. The care team can better manage co-occurring conditions and reduce the risk for falls and injuries; better management may lessen secondary disorders and enhance quality of life. Also, individuals with an early diagnosis can create advance directives for their care and finances.

Why does public health need to act?

Early detection and diagnosis – a core public health service – is essential to protecting the wellbeing and safety of people with Alzheimer's disease and other dementias. **Unfortunately, as many as half of people with dementia have never received a diagnosis**. Moreover, according to the Centers for Disease Control and

Prevention, of those who have been diagnosed with Alzheimer's or another dementia, only 35 percent of them or their caregivers are aware of the diagnosis. In contrast, more than 90 percent of seniors with cancer or cardiovascular disease have been told their diagnosis.

Responding to this disparity, <u>Healthy People 2020</u> has set a goal to increase diagnosis disclosure by 10 percent over the decade. And, the Medicare Annual Wellness Visit (AWV) includes a requirement for detection of possible cognitive impairment.

Increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis.

-Healthy People 2020, Objective DIA-1

What can the public health community do to increase diagnosis of Alzheimer's disease?

Early detection and diagnosis are part of the <u>public health response</u> to Alzheimer's disease. Public health and its partners can take three basic steps to help individuals and health care providers discuss memory problems.

- Build public awareness about the warning signs of dementia and the benefits of early diagnosis, such as
 using the <u>10 Warning Signs</u> in agency websites or public awareness campaigns.
- Educate health care professionals on both the importance of detecting problems with cognition (including
 using the Medicare AWV to <u>discuss memory issues</u> and administer <u>validated cognitive assessment tools</u>)
 and the need to disclose a diagnosis of Alzheimer's or other dementia.
- Promote best practices, such as recommendations from the <u>Gerontological Society of America's</u> expert workgroup regarding diagnosis and care planning in primary care settings.

Updated December 2015

Learn more at: alz.org/publichealth



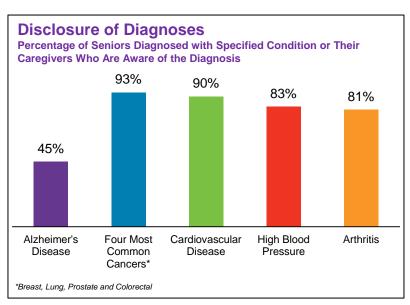
policybrief

DECEMBER 2015 alz.org®

Early Detection and Diagnosis of Alzheimer's Disease

Quality care for Alzheimer's disease and other dementias starts with an early, documented diagnosis, including disclosure of the diagnosis. However, among individuals living with Alzheimer's and other dementias, evidence indicates about half have not been diagnosed. And of those who have been diagnosed, less than half are aware of their diagnosis. Only 45 percent of adults age 65 and older diagnosed with Alzheimer's, or their caregivers, are aware of the diagnosis. Among individuals diagnosed with Alzheimer's, only 33 percent are aware of the diagnosis. These data are comparable to baseline data from *Healthy People 2020*, the nation's 10-year public health agenda, that indicate approximately 35 percent of Medicare beneficiaries age 65 and older diagnosed with dementia, or their caregivers, were aware of the diagnosis. ²

To address this challenge, *Healthy People 2020* includes the objective to "increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis." To make progress on this objective, actions include assuring the public and health care providers know the early warning signs of Alzheimer's; educating health care providers on early detection and diagnosis, including patient/family communications and documentation in medical records; and assessing cognition during the Medicare Annual Wellness Visit (AWV). These actions, among others, provide a foundation for the delivery of quality dementia care.



Benefits and barriers for early detection and diagnosis

Alzheimer's disease, the most common cause of dementia, is a disabling chronic condition characterized by symptoms such as increased confusion, memory loss and impaired judgment.¹ These symptoms impede daily activities and the management of comorbid conditions, and can lead to functional decline, significant caregiver burden and long-term disability. Although Alzheimer's is not a normal part of aging, age is the biggest risk factor: only an estimated 4 percent of Alzheimer's cases occur among those under the age of 65; of those 85 years and older, 32 percent have the disease.¹ With the aging of the Baby Boom Generation, an increasing number of Americans will

move into the age range where they will be at higher risk of developing Alzheimer's and other dementias and could benefit from increased efforts at promoting early detection and diagnosis.

Benefits of early detection and diagnosis

Early detection and diagnosis offers a number of benefits to help affected individuals and their families. Early detection and diagnosis allows people to access available treatments, build a care team, participate in support services, and enroll in clinical trials. People who know they have the disease and their caregivers can create advance health directives and make financial and legal arrangements before cognition further declines. They can also address safety issues and seek counseling on how to cope with behavioral changes associated with disease progression.¹

Early detection can also help health care providers deliver better care. Early detection can help physicians better manage a patient's comorbid conditions and avoid prescribing medications that may worsen cognition or function.³ And because early warning signs such as memory problems, confusion, personality changes and trouble with judgment^{4,5} may be attributable to other sources, early detection of cognitive changes allows physicians to identify and treat reversible conditions that mimic cognitive impairment and dementia such as depression or vitamin deficiency.¹

Furthermore, early detection and diagnosis of Alzheimer's and other dementias may help to reduce unmet needs of affected individuals who are more likely to experience disability. Among Medicare beneficiaries who report being aware of their diagnosis, 57 percent required assistance with three or more activities of daily living (ADLs) and 59 percent required assistance with three or more instrumental activities of daily living (IADLs). Data from the 2011 Behavioral Risk Factor Surveillance System (BRFSS) found those with self-reported confusion or memory loss – often referred to as subjective cognitive decline – and functional difficulties were more likely to report frequent poor health, limited activity due to poor

U.S. Preventive Services Task Force

The U.S. Preventive Services Task Force, a group of national experts who develop recommendations on clinical preventive services and evidence-based medicine, has concluded there is "insufficient evidence" to recommend for or against routine screening for cognitive impairment in asymptomatic older adults. However, the Task Force stated that "clinicians should remain alert to early signs or symptoms of cognitive impairment and evaluate as appropriate." The Task Force also recognized cognitive impairment as a serious public health issue and encouraged consumers experiencing memory problems to speak with a their health care providers.

Final Recommendation Statement: Cognitive Impairment in Older Adults: Screening, U.S. Preventive Services Task Force. 2014.

physical or mental health, and a need for more assistance. ⁶

Barriers to early detection and diagnosis

For early detection to occur – and subsequent diagnosis and disclosure awareness - patients and physicians must overcome several barriers. Patients face barriers such as low public awareness of the early signs of Alzheimer's, including notable differences in diverse populations;^{7,8} perceived emotional distress of Alzheimer's and other dementias on family members;9 and misperceptions about Alzheimer's and other dementias. 10,11 For example, a recent survey of 12 countries found 59 percent of respondents incorrectly believed that Alzheimer's is a typical part of aging, and 40 percent believed that Alzheimer's is not fatal. 12 These barriers can lead to stigma, delays in seeking medical assistance or reluctance to communicate with health care providers. Data from the 2012 BRFSS showed only 23 percent of adults age 45 and older who reported subjective cognitive decline in the previous 12 months had talked with a health care provider about it. 13

Physicians face barriers such as low recognition of the signs of cognitive impairment; a lack of education or training on dementia care; concerns about stigma and the usefulness of an early diagnosis; lack of time; and

difficulty talking about dementia or disclosing a diagnosis. 1,14,15,16 Contributing to these challenges are low rates of documentation of diagnoses in patients' medical records. Less than half of those with Alzheimer's and dementia diagnoses have it documented in their medical records. 14,17,18 Research also indicates low rates of documentation for mild cognitive impairment, even if doctors recognize and diagnose it. 15

Detection/assessment of cognitive change

Experts agree establishing a cognitive baseline in a medical setting can assist health care providers with identifying changes in cognition that merit further evaluation. ¹⁹ Consistent with this, detection of possible cognitive impairment is a mandatory element of the Medicare Annual Wellness Visit (AWV). ²⁰ As previously noted, because early signs and symptoms of cognitive impairment and dementia may be characteristic of other health conditions, these routine, brief cognitive assessments are an important way for physicians to detect notable change over time that could indicate underlying pathology.

The National Institute on Aging (NIA), ²¹ the Gerontological Society of America (GSA)²² and the Alzheimer's Association¹⁹ have developed evidence-based guidelines to advise health care providers on how to detect cognitive impairment in primary care settings, including during the Medicare AWV. Although expert groups have not recommended a single preferred instrument, there is consensus that tools for the detection of cognitive impairment should be short, easy to administer, and validated for use in primary care settings. ^{19,21,22} If cognitive impairment is detected, health care providers can then refer patients for comprehensive diagnostic evaluations.

In addition to employing a brief assessment tool for detection, these guidelines recommend physicians incorporate informant interviews and self-reports. A growing body of evidence suggests subjective cognitive decline (SCD) may be a harbinger of subsequent cognitive impairment or dementia, including Alzheimer's. Studies have shown SCD to be

associated with increased risk of MCI or dementia; ²³ significant decline in episodic memory; ²⁴ early Alzheimer's pathology such as the buildup of beta-amyloid; ²⁵ and memory decline in people who carry the apolipoprotein E (APOE)-e4 gene, ²⁶ a genetic risk factor for Alzheimer's. As research continues, health care providers may be able to employ SCD as a clinical complement to other cognitive detection tools.

What can be done?

Early detection and diagnosis of Alzheimer's disease and other dementias helps affected individuals achieve better quality care by identifying cognitive impairment as early as possible. As with other chronic conditions, early identification and management of Alzheimer's and other dementias helps people better understand and anticipate care needs as they arise. Because of the progressive nature of the disease on functioning, the best opportunity for individuals to benefit from available treatments, express their wishes, and plan for the future is in the early stages. The following public policies can help promote early detection and diagnosis, and ultimately support the health outcomes of affected individuals.

> Raise public awareness about the signs and symptoms of Alzheimer's disease and other dementias – and the importance of early detection and diagnosis. Educating the public about Alzheimer's disease and other dementias and early detection can increase understanding about what cognitive impairment looks like, dispel myths and encourage individuals to talk with their health care providers. Federal, state and public health agencies can share information with the public on the early warning signs and the importance of talking with a health care provider when experiencing memory problems. Outreach should include faith-based groups and diverse communities, and be translated to languages appropriate for local audiences. Large employers can be encouraged to participate in the Alzheimer's Workplace Alliance® (AWA), which aims to raise awareness about Alzheimer's disease and the importance of early detection while

providing help to those who are balancing work and caregiving responsibilities.²⁷

- Promote participation in the Medicare Annual Wellness Visit (AWV). The Medicare AWV provides an excellent opportunity for physicians to discuss healthy aging with patients, including risk factors for cognitive decline and guidance on lifestyle and behavioral changes that can support brain health.²⁸ Public health, aging and health professionals' organizations can educate the public on the importance of this annual health visit by providing information on what it entails in easy-to-read, language-appropriate materials. They can also educate physicians on how to detect cognitive impairment and use validated cognitive assessment tools and quick references such as the Alzheimer's Association Cognitive Assessment Toolkit, 29 a quide for detecting cognitive impairment during the Medicare AWV.
- > Educate health care providers. State agencies and provider groups should share information with physicians about early detection and diagnosis, including the importance of disclosing a diagnosis and medical record documentation. For example, the New York State Department of Health sent a "Dear Colleague" letter to all primary care providers in the state³⁰ to convey the benefits of early detection, validated cognitive assessment tools, and indications for referral for further evaluation. State agencies can also partner with medical associations to develop and post a "tool box" on their web sites that includes information about Alzheimer's disease and other dementias, community resources and continuing education courses³¹ that can help health care professionals improve their ability to recognize the early warning signs and provide appropriate care for affected individuals.
- ➤ <u>Collect data on early detection and cognition</u>. While the Medicare AWV requires "detection of cognitive impairment," there is currently no way to track if physicians are actually doing it. Medical associations, consumer health groups, and public health entities can partner to periodically survey

- health care providers in their states to find out how often physicians discuss cognitive health during the AWV and what tools they use with patients who have symptoms suggestive of cognitive impairment. The surveys would inform efforts to enhance use of the AWV in increasing early detection. State public health agencies can also adopt the Cognitive Module in their annual BRFSS surveys to capture state-specific data on cognitive decline (including discussions with health care providers), and use this information to inform actions for interventions.
- Support research on outcomes of early detection. Additional research is needed to evaluate outcomes of early detection for cognitive impairment, specifically the impact detection has on patient and caregiver decision-making and societal outcomes.
- ➤ Pass the HOPE for Alzheimer's Act. One reason doctors do not disclose an Alzheimer's diagnosis is be-cause of the insufficient time and resources available to provide support at the time of diagnosis. The HOPE for Alzheimer's Act (S. 857/H.R. 1559) would provide Medicare coverage for comprehensive care planning services and medical record documentation of both the diagnosis and the care planning. It would also require the U.S. Department of Health and Human Services to conduct provider outreach about the new benefit, identify barriers beneficiaries face in accessing care planning services and make recommendations to eliminate them.

Conclusion

Detecting cognitive impairment, diagnosing Alzheimer's disease and other dementias, and disclosing that diagnosis to the individual are necessary elements to ensuring those with the disease and their families have the opportunity to access available treatments, build a care team, participate in support services, enroll in clinical trials, and plan for the future. Policies to promote early detection and diagnosis – among the public and health care providers – can ensure those opportunities are available.

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PowerPoint Script



Slide 1

Welcome to the Know the 10 Signs: Early Detection Matters program, developed by the Alzheimer's Association and presented by Kansas State Research and Extension.

The Early Detection project is important because currently many people go undiagnosed with Alzheimer's disease for years, which causes them to lose valuable time that could be spent planning for the future and managing symptoms.



Slide 2

To begin, I would like to share this quote with you.

This highlights the importance of early detection of Alzheimer's disease, and why I am here talking with you today.



Slide 3

Today, you'll be given the opportunity to hear from people with the disease and their family members talking about their lives with Alzheimer's disease. This is a chance to see real people telling you the truth about their journey, from the first sign of a problem through diagnosis and early adjustment. Some of it will sound very, very familiar to those of you with concerns. Some of it will be new for you – new information, new ideas, and new ways of looking at things. And parts of it will amaze you, when you see how these individuals have learned to adapt themselves, their families, their daily activities and their views of themselves to come to terms with Alzheimer's disease.

Slides 4 and 5

Video Clip Intro:

Here is our first film clip, showing Mary Ann, who is living with Alzheimer's disease, talking about the stigma associated with the disease.

View Video Clip

Presenter's Note:

Please insert your own 1-2 sentence comment about the video clip here. Important points from the film:

- This was once viewed with shame.
- Stereotypes still exist.
- Next wave you won't be the only one you know who is dealing with this.

Slide 6

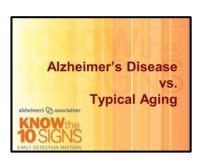
Let's start by looking at the differences between Alzheimer's and typical aging.

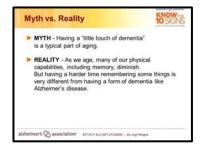
Slide 7 (Refer to Quiz Question #1)

The MYTH is that – Having a "little touch of dementia" is a normal part of aging.

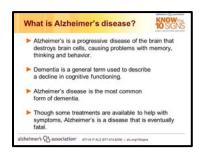
The REALITY is – Our brains age right along with the rest of our bodies, and our abilities naturally change with age. But this aging process is different from the disease process that accompanies a diagnosis of Alzheimer's.







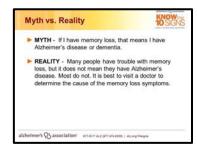
For many years, we thought that aging included a list of changes, and we believed that having at least some of those changes was inevitable. We called some of the memory loss changes "senility" or "hardening of the arteries." Those were thought to be a natural part of aging. Now we know that they are actually symptoms of a number of diseases, including Alzheimer's disease.



Slide 8

Alzheimer's is a disease of the brain that progressively destroys brain cells, causing problems with memory, thinking and behavior. In the early stages of Alzheimer's, the affected person may experience memory impairment, lapses of judgment, and subtle changes in personality. This is because the hippocampus is attacked first (the hippocampus is in charge of emotions and memory). As the disorder progresses, new areas of the brain are affected, memory and language problems worsen, as do movement and perception. There may be disorientation and personality changes.

Dementia is a general term used to describe a decline in cognitive functioning. Alzheimer's disease is the most common form of dementia.



Slide 9 (Refer to Quiz Question #2)

The MYTH is that – If I have memory loss that means I have Alzheimer's disease or dementia.

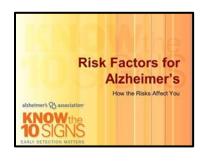
The REALITY is – Most people who have memory loss do not have Alzheimer's disease, and there are many other diagnoses that have memory loss as a symptom. The person who can determine the cause of the memory loss symptoms is a doctor, so be sure to consult a physician to make a thorough diagnosis.

Optional: Present the Brain Tour (www.alz.org/braintour)

Slide 10

There are a number of risk factors for dementia, **but most** of them will not predict whether or not you will develop Alzheimer's disease or other related dementia.

However, you can benefit from knowing the risks. Once you know the risks, you will be able to make changes to your lifestyle that may positively affect your brain health.



Slide 11

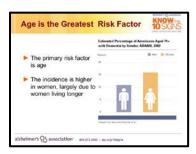
The single biggest factor for dementia is **age**. Youngeronset Alzheimer's disease is unusual – it totals less than 5% of all cases.

Women appear to be at greater risk for developing dementia in their lifetimes. Almost two-thirds of Americans with Alzheimer's are women. The prevailing view of why this occurs has been simply that women live longer than men. However, limited new research suggests that the difference may be due to biological or genetic variations, or different life experiences such as type and amount of education or occupational choices. Additional scientific investigation will need to be done before we thoroughly understand the nature of women's higher rates of dementia.

Other issues that factor into the calculation of risk for dementia include **socioeconomic factors**, and those affect people's ability to provide themselves with good medical care, proper diet, and intellectual stimulation.

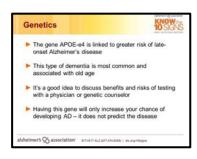
Slide 12 (Refer to Quiz Question #3)

The MYTH is that – If Alzheimer's disease runs in your family, genetic testing will tell you whether you will get Alzheimer's disease too.





The REALITY is – There are no clear-cut tests to diagnose Alzheimer's disease during life. The only true diagnosis can occur during an autopsy.



Slide 13

Scientists have discovered a gene which is linked to a greater risk of developing late-onset Alzheimer's. That's the most common form of the disease. It shows symptoms after the age of 65 and is generally associated with old age.

There are three versions of that gene, and each is associated with different levels of increased risk for developing Alzheimer's. However, although having that gene increases the risk of developing Alzheimer's, but it does not tell you whether or not you will develop the disease. If you are considering genetic testing, be sure to discuss the idea with your doctor and a genetic counselor.

Three other genes, though, are linked to the younger-onset forms of Alzheimer's in which symptoms usually begin to appear between a person's early 40s and mid-50s. If someone has a mutation of one of these genes, he or she has a 95-100% chance of developing the disease at some point. These incidents of Alzheimer's are very rare, accounting for less than one percent of all cases. Affected families are usually well aware of their unique history with the disease.



Slide 14

Body-brain connection: There is scientific evidence about dementia that links brain health to heart health. Your brain is nourished by one of your body's richest networks of blood

vessels. The risk of developing Alzheimer's or vascular dementia appears to be increased by conditions that damage the heart or blood vessels. These include high blood pressure, heart disease, stroke, diabetes and high cholesterol.

African Americans, Latinos and other groups that tend to have high percentages of hypertension and diabetes need to be particularly aware of these risks. But when these factors are brought under control with diet, exercise and appropriate medications, no differences between ethnicities are shown in the rates of dementia. Everyone should work with their doctors to monitor heart health and to treat any problems that arise.

Slide 15

Early detection comes before an Alzheimer's diagnosis. It is personal acknowledgment of possible symptoms of Alzheimer's coupled with the willingness to talk about it and to take action.



Slide 16

Memory changes that disrupt daily life

With typical aging, a person sometimes forgets names or appointments but remembers them later.

One of the most common signs of Alzheimer's, especially in the early stages, is **forgetting recently learned information**. Others include forgetting important dates or events, asking for the same information over and over, relying on memory aids like reminder notes or electronic devices, or relying on family members for things the person used to handle on their own.





Slides 17 and 18

Video Clip Intro:

Sue talks about developing a coping strategy for this warning sign in the next video clip.

View Video Clip

Presenter's Note:

Please insert your own 1-2 sentence comment about the video clip here. Important points from the film:

- There are some creative strategies that each person can develop to help them remember things.
- Using those strategies can be part of the challenge.
- It's important to keep a sense of humor.



Slide 19

Challenges in planning or solving problems

With typical aging, people may make occasional errors when balancing a checkbook.

But with Alzheimer's, some people may experience changes in their abilities. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.



Slide 20

Difficulty completing familiar tasks

Typical aging involves occasionally needing help to use the settings on a microwave or to record a television show.

People with Alzheimer's often find it **hard to complete daily tasks** like shopping, cooking, personal grooming or medical care.

Sometimes, people may have trouble driving to a familiar location, managing a budget at work, or remembering the rules of a favorite game.

Slides 21 and 22

Video Clip Intro:

In our next film clip, Joyce, who lives with Alzheimer's disease and vascular dementia, talks about being surprised by having this warning sign.

View Video Clip

Presenter's Note:

Please insert your own 1-2 sentence comment about the video clip here. Important points from the film:

- There can be unexpected challenges with the disease.
- Meeting the challenges can be an emotional adjustment.

Slide 23

Confusion with time or place

With typical aging, a person may sometimes get confused about the day of the week but figure it out later.

People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.







Slide 24

Trouble understanding visual images and spatial relationships

Typical aging includes vision changes related to the aging of the eyes, like cataracts.

But for **some** people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. Perception and judging distances have very real implications for driving. The use of rear view mirrors and side mirrors while driving is key to safety. But for someone with the disease, using all of these mirrors while processing the changing view in front of them, and looking over their shoulders to back up, is overwhelming to their senses – it's too much information! They may become upset or make mistakes, both of which can lead to accidents.



Slide 25

New problems with words in speaking or writing
Typical aging includes sometimes having trouble finding the right word.

People with Alzheimer's may have **trouble following or joining a conversation**. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word, or call things by the wrong name (like calling a "watch" a "hand clock").

Slides 26 and 27

Video Clip Intro:

Joyce talks about how she first noticed this particular warning sign in the next video clip.

View Video Clip

Presenter's Note:

Please insert your own 1-2 sentence comment about the video clip here. Important points from the film:

- One aspect of this sign is that writing may take much longer than in the past and may not be clear to others.
- Needing to ask for assistance with tasks that you used to know how to do can be an indication of a problem.

Slide 28

Misplacing things and losing the ability to retrace steps

Typical aging involves misplacing things from time to time, such as a pair of glasses or the remote control.

A person with Alzheimer's disease may **put things in unusual places**. For example, a person might put shoes in the freezer or milk in the attic. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.

Misplacing things and losing the ability to retrace steps Putting things in unusual places e.g., wallet in fruit bowl Having increasing difficulty retracing steps to locate a missing item Accusing others of stealing

<u>Slide 29</u>

Decreased or poor judgment

Typical aging involves making a bad decision once in a while.

People with Alzheimer's may experience **changes in judgment or decision making**. For example, they may use poor



judgment when dealing with money, giving large amounts to telemarketers. They may become less able to choose clothing that is appropriate to the weather or the season.

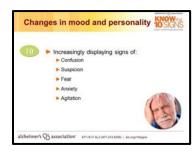


Slide 30

Withdrawal from work or social activities

With typical aging, someone may periodically feel weary of work, family and social obligations.

A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or family gatherings. They may have trouble keeping up with a favorite sports team or remembering how to engage in a favorite hobby. They may also avoid being social because it be-comes harder and harder to follow conversations.



Slide 31

Changes in mood and personality

Typical aging can involve developing very specific ways of doing things and becoming irritable when a routine is disrupted.

But the mood and personalities of people with Alzheimer's can change with the disease. It is much easier for someone with dementia to do things in very routine ways, with not much change or variety. They can become **confused**, **suspicious**, **depressed**, **fearful or anxious** when situations call for spontaneous changes or quick responses. As a result, they may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

Slide 32

So what should you do if you see these signs in yourself or someone else?

First and foremost, talk about it! Talk with people about what you are seeing and what you are thinking. Discuss your suspicions. Break the silence about this disease that keeps people from getting the medical care they need.

Encourage anyone with symptoms to **see a doctor** to find out the cause. Some causes of the signs can be treated or reversed – and some might even be life threatening!

Getting the right treatment as soon as possible is crucial no matter what the diagnosis. It's easy to let things slide. But you can change or even save a life by continuing to talk and follow up.

Together we can break the stigma that keeps people from getting the help they need.

What should I do if I see some of the 10 signs? Talk with people about what you are seeing and thinking A visit to the doctor is indicated Getting the right treatment as soon as possible is crucial

Slide 33 and 34

Video Clip Intro:

In our next clip, we'll see Susan give some advice to families dealing with the changes they see in their loved ones.

View Video Clip

Presenter's Note:

Please insert your own 1-2 sentence comment about the video clip here. Important points from the film:

- Advice for families: Be gentle but straightforward
- Don't be afraid to talk about it.





Slide 35

After detecting warning signs, the next step is getting a thorough assessment from a doctor. The diagnosis may not be Alzheimer's at all - it may be a completely different diagnosis. But no matter what the diagnosis turns out to be, early diagnosis is critical.



Slide 36 (Refer to Quiz Question #4)

The MYTH is – There's no point in getting diagnosed, because dementia is not curable or treatable. It will just upset my family and me, so why do it?

The REALITY is that – There are a number of very good reasons to pursue a diagnosis. Let's talk a look at them now.



Slide 37

Once the person with symptoms sees the doctor, they may discover that they actually don't have dementia at all, but have another illness. Some of the illnesses that can cause memory problems are treatable and can be reversed – like depression or thyroid problems.

Other illnesses that can cause memory problems can be life threatening if not detected and treated promptly – like heart problems or high blood pressure that has caused ministrokes. These need to be diagnosed and treated right away to avoid even more serious damage. It's important not to ignore changes or to assume that it is Alzheimer's.

Slide 38 (Refer to Quiz Question #5)

The MYTH is that – You don't need a complete set of diagnostic tests to know if you have Alzheimer's disease. You can just try a medication for memory loss – if it works, you know.

The REALITY is that – There are many types of dementia and they are dealt with differently. A number of tests will need to be done in order to get the most accurate diagnosis. If you get a diagnosis without having all of these tests done, ask your doctor to refer you to a specialist who can complete them. Only with a complete and thorough diagnosis can you know what you're dealing with and how to treat it.

Myth vs. Reality MYTH - You don't need a complete set of diagnostic tests to know if you have Alzheimer's disease. You can just try a medication for memory loss – if it works, you know. REALITY - Early treatment is best, but you have to know what you're treating. There are many things that can cause memory loss and it is important to be thoroughly assessed.

Slide 39 and 40

Video Clip Intro:

Here's Gary talking about the time it takes to get a diagnosis.

View Video Clip

Presenter's Note:

Please insert your own 1-2 sentence comment about the video clip here. Important points from the film:

- Doctors need to take their time making a diagnosis.
- They need to rule out other diseases first before settling on a diagnosis of Alzheimer's disease.





Slide 41

Experts estimate a skilled physician can diagnose Alzheimer's with more than 90 percent accuracy, but there is **no single test that proves that a person has Alzheimer's.**

The medical workup is designed to evaluate overall health and identify any conditions that could affect how well the mind works. The doctor will interview the person being examined or family members to gather information about current and past illnesses and will ask about specific symptoms. They will do a physical examination and testing of blood and urine to help identify other disorders with similar symptoms.

The doctor will also do mental status testing, which gives a general idea of whether a person:

- Is aware of having symptoms or feels nothing is wrong.
- Knows the date, time and where he or she is.
- Can remember a short list of words, follow instructions and do simple calculations.

In addition to assessing mental status, the doctor will evaluate a person's sense of well-being to detect depression or other mood disorders that can cause memory problems, loss of interest in life, and other symptoms that can overlap with dementia.

The neurological examination is an important part of the physical. Its goal is to assess the function of the brain and nervous system to identify symptoms of brain disorders other than Alzheimer's.

During the neurological exams, the physician may test:

- Reflexes
- Coordination and balance
- Muscle tone and strength
- Eye movement
- Speech

Currently, a standard medical workup for Alzheimer's disease often includes brain imaging with an MRI or CT scan or, less frequently, a PET scan. These images are used primarily to detect tumors, evidence of small or large stroke, and damage from severe head trauma or a buildup of fluid. Although a certain amount of brain shrinkage comes with age, research has shown that greater levels of shrinkage in specific brain regions may be an early sign of Alzheimer's. However, scientists have not yet agreed upon standardized values that would establish the significance of a specific amount of shrinkage for any individual person at a single point in time. In the future, there may be a role for these tests in directly diagnosing dementia as well.

Slide 42

Information from these tests can help identify other disorders that may cause memory loss, confused thinking, trouble focusing attention, or other symptoms similar to dementia. In addition to the disorders listed on this slide, others include:

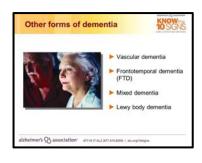
- Diabetes.
- Kidney or liver disease.
- Thyroid abnormalities.
- Problems with the heart, lung or blood vessels.

Slide 43

There are other important forms of dementia including:

Vascular dementia, which typically develops when a stroke impairs blood flow to parts of the brain.





Mixed dementia, which is the second most common type of dementia. It is a condition in which Alzheimer's disease and vascular dementia occur at the same time.

Frontotemporal dementia (FTD) has symptoms that include behaviors that are usually associated with mood rather than memory – apathy, withdrawal, and lack of motivation.

Lewy body dementia has symptoms which include visual hallucinations, stiffness, shuffling, shakiness, and sleep disorders, including acting out dreams while awake.



Slide 44

Not everyone who seeks a diagnosis will be diagnosed with Alzheimer's disease or another dementia. But for those who are, there are things that can be done to improve functioning and care.



Slide 45

With Early Diagnosis, you can get the maximum benefit from available treatments. You can explore treatments that may provide some relief of symptoms and help you maintain independence. You may also increase your chances of participating in clinical drug trials that offer high standards of care and also help advance research.



Slides 46 and 47

Video Clip Intro:

In our next film, Jestene, who is 75 and has been living with Alzheimer's disease for a year, talks about the importance of early diagnosis.

View Video Clip

Presenter's Note:

Please insert your own 1-2 sentence comment about the video clip here. Important points from the film:

- Get started with medications early to get the most help from them.
- Early treatment can help someone with Alzheimer's disease live a more productive life.

Slide 48

There are medications designed to help **relieve some symptoms**, **but not to stop the disease progression**. Some medications, such as cholinesterase inhibitors, may *temporarily* improve memory or slow down memory loss. Other drugs are available to help with mood and behavior changes. Talk to your doctor about which treatment options are best for your situation.



Slide 49

With early diagnosis, you can have more time to plan for the future. A diagnosis of Alzheimer's allows the person with dementia to take part in decisions about care, living arrangements, transportation, and safety, financial and legal matters. These plans are made much more easily before they are needed. Everyone involved can also participate in building the right care team and social support net- work with a timely diagnosis.





Slide 50

One of the best things we all can do for our families and ourselves is to get legal, financial and care plans in place.

You should complete your advance healthcare planning documents (Advance Healthcare Planning in Kansas -- through KSRE bookstore) and seek legal advice and services from attorney who is knowledgeable about legal issues for seniors.

Some of the planning issues include:

- Identifying and completing legal documents,
- Making plans for medical and treatment decisions,
- Making plans for finances and property, and
- Naming another person to make decisions on your behalf when you no longer can.

Doing this allows you to participate in making decisions and ensures your family won't be forced to make them for you in a crisis situation. To find an attorney who specializes in elder care, visit the National Academy of Elder Law Attorneys website, or contact the Alzheimer's Association.



Slide 51

Now, let's look at some resources that can help your whole family.

Slide 52

There are many chapters of the Alzheimer's Association located throughout the country. Each chapter offers many services and programs for people living with Alzheimer's disease and their families. You can find your local chapter at www.alz.org.



Slide 53

The goal for people who have been diagnosed is to live meaningful, active lives for as long as they can. That's the goal for all of us! There are many resources now available to help people who have been diagnosed with a dementia live with purpose for as long as possible.

You can add your skills, motivation and voice to the cause, with fundraising and advocacy efforts to help those with dementia and their families.



Slide 54

So let's recap:

- If you notice any of the 10 Warning Signs in yourself or someone else, talk about it!
- Then check it out with your doctor. It may be typical aging or it may be something that you need to pursue.



- It's important to know what you're dealing with. Get a thorough set of tests from your doctor to find out why the symptoms are occurring and what needs to be done to address it.
- Be sure to follow up on all the recommendations that your doctor gives you and build the team you need to address the issues you are facing.
- If it is a form of dementia, the Alzheimer's Association can help you and your family. Their 24-hour toll free phone number is 1.800.272.3900.



Slides 55 and 56

Video Clip Intro:

Here's Mimi, who lives with Alzheimer's disease, to sum things up for all of us.

As Mimi reminds us, there is reason to hope. Great things are happening now in research at a rapid pace, and the programs and services offered through the Alzheimer's Association are helping more people than ever who are affected by dementia.

Slide 57



Here is the phone number for the Alzheimer's Association's 24 hour Helpline, where there are professionals available every day of the year to speak with you. The website is also shown, and is a great source of information about dementia and building a supportive team. Please feel free to use both of these resources any time you'd like, and to contact your Extension agent and Alzheimer's Association chapter for local resources, education and support.

Central and Western Kansas Chapter (Wichita): 316.267.7333
Heart of America Chapter (Prairie Village): 913.831.1916
NE Regional Office (Topeka): 7853.271.1844

NE Regional Office (Topeka): 7853.271.1844 SE Regional Office (Parsons): 620.421.6550

Let's go back to the myths and realities worksheets that you received at the beginning of the program and talk about it a little bit. Now, how do you think you did on the Worksheet? Maybe you changed some of your answers as we went along. Let's go through it together to see what you learned today about Early Detection. One thing that you'll notice is that all of the questions are myths and are false. Let's correct these mistaken assumptions.

Number 1: Having a "little touch of dementia" is a normal part of aging.

That is false: As we age, many of our physical capabilities including memory diminish. But having a harder time remembering some things is very different from having a form of dementia like Alzheimer's disease.

Number 2: If I have memory loss, that means I have Alzheimer's disease or dementia.

This is false. What it means is that you have a symptom, and you should see your doctor to get a thorough assessment and diagnosis.

Number 3: If Alzheimer's disease runs in your family, genetic testing will tell you whether you will get Alzheimer's disease too.

This is false. Having a parent or sibling with Alzheimer's dis-ease does somewhat increase someone's risk of developing the disease, but genetics is not the only risk factor.

Number 4: There's no point in getting diagnosed, because dementia is not curable or treatable. It will just upset my family and me, so why do it?

This is false. Early diagnosis is the only way to get early treatment for any diagnosis.

Number 5: You don't need a complete set of diagnostic tests to know if you have Alzheimer's disease. You can just try a medication for memory loss - if it works, you know.

This is false. Early treatment is best, but you have to know what you're treating. There are many things that can cause memory loss and it is important to be thoroughly assessed.

Are there any questions or comments about what you've learned today?

The Brain Tour

1. Three pounds, three parts





Your brain is your most powerful organ, yet weighs only about three pounds. It has a texture similar to firm jelly.

It has three main parts:

- 1. The cerebrum fills up most of your skull. It is involved in remembering, problem solving, thinking, and feeling. It also controls movement.
- 2. The cerebellum sits at the back of your head, under the cerebrum. It controls coordination and balance.
- 3. The brain stem sits beneath your cerebrum in front of your cerebellum. It connects the brain to the spinal cord and controls automatic functions such as breathing, digestion, heart rate and blood pressure.





2. Supply lines





Your brain is nourished by one of your body's richest networks of blood vessels.

With each heartbeat, **arteries** carry about 20 to 25 percent of your blood to your brain, where billions of cells use about 20 percent of the oxygen and fuel your blood carries.

When you are thinking hard, your brain may use up to 50 percent of the fuel and oxygen.

The whole vessel network includes veins and capillaries in addition to arteries.

← GO TO BRAIN TOUR SLIDE 1



3. The cortex: "Thinking wrinkles"





Your brain's wrinkled surface is a specialized outer layer of the cerebrum called the cortex. Scientists have "mapped" the cortex by identifying areas strongly linked to certain functions.

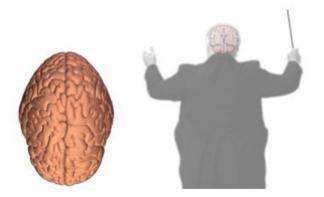
Specific regions of the cortex:

- Interpret sensations from your body, and sights, sounds and smells from the outside world.
- Generate thoughts, solve problems and make plans.
- Form and store memories.
- Control voluntary movement.

← GO TO BRAIN TOUR SLIDE 1



4. Left brain/right brain





Your brain is divided into right and left halves. Experts are not certain how the "left brain" and "right brain" may differ in function, except:

- The left half controls movement on the body's right side.
- The right half controls the body's left side.
- In most people, the language area is chiefly on the left.

← GO TO BRAIN TOUR SLIDE 1



5. The neuron forest





The real work of your brain goes on in individual cells. An adult brain contains about 100 billion nerve cells, or neurons, with branches that connect at more than 100 trillion points. Scientists call this dense, branching network a "neuron forest."

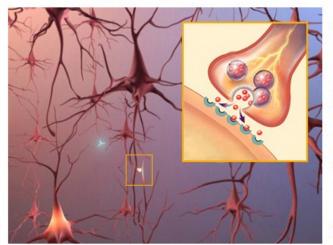
Signals traveling through the neuron forest form the basis of memories, thoughts, and feelings.

Neurons are the chief type of cell destroyed by Alzheimer's disease.





6. Cell signaling



← NEXT →

Signals that form memories and thoughts move through an individual nerve cell as a **tiny electrical charge**.

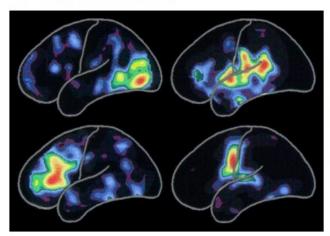
Nerve cells connect to one another at synapses. When a charge reaches a synapse, it may trigger release of tiny bursts of chemicals called neurotransmitters. The neurotransmitters travel across the synapse, carrying signals to other cells. Scientists have identified dozens of neurotransmitters.

Alzheimer's disease disrupts both the way electrical charges travel within cells and the activity of neurotransmitters.

← GO TO BRAIN TOUR SLIDE 1



7. Signal coding





100 billion nerve cells. 100 trillion synapses. dozens of neurotransmitters. This "strength in numbers" provides your brain's raw material. Over time, our experiences create patterns in signal type and strength. These patterns of activity explain how, at the cellular level, our brains code our thoughts, memories, skills and sense of who we are.

The positron emission tomography (PET) scan on the left shows typical patterns of brain activity associated with:

- Reading words
- · Hearing words
- · Thinking about words
- Saying words

Activity is highest in red areas and then decreases through the other colors of the rainbow from yellow to blue-violet.

Specific activity patterns change throughout life as we meet new people, have new experiences and acquire new skills. The patterns also change when Alzheimer's disease or a related disorder disrupts nerve cells and their connections to one another.



8. Alzheimer's changes the whole brain ← NEXT →



Alzheimer's disease leads to nerve cell death and tissue loss throughout the brain. Over time, the brain shrinks dramatically, affecting nearly all its functions.

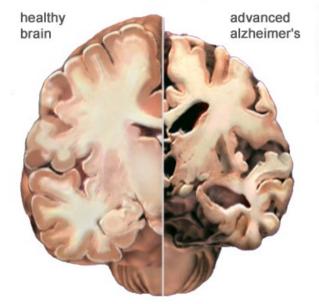
These images show:

- · A brain without the disease
- A brain with advanced Alzheimer's
- How the two brains compare

← GO TO BRAIN TOUR SLIDE 1



9. More brain changes





Here is another view of how massive cell loss changes the whole brain in advanced Alzheimer's disease. This slide shows a crosswise "slice" through the middle of the brain between the ears.

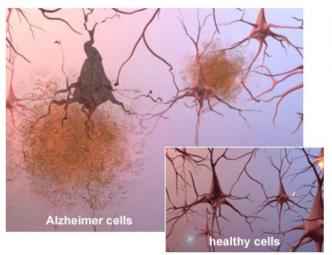
In the Alzheimer's brain:

- The cortex shrivels up, damaging areas involved in thinking, planning and remembering.
- Shrinkage is especially severe in the hippocampus, an area of the cortex that plays a key role in formation of new memories.
- Ventricles (fluid-filled spaces within the brain) grow larger.

← GO TO BRAIN TOUR SLIDE 1



10. Under the microscope





Scientists can also see the terrible effects of Alzheimer's disease when they look at brain tissue under the microscope:

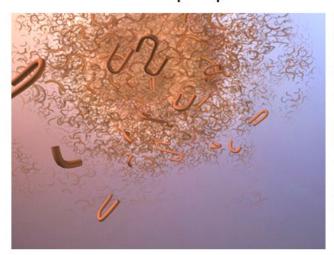
- Alzheimer's tissue has many fewer nerve cells and synapses than a healthy brain.
- Plaques, abnormal clusters of protein fragments, build up between nerve cells.
- Dead and dying nerve cells contain tangles, which are made up of twisted strands of another protein.

Scientists are not absolutely sure what causes cell death and tissue loss in the Alzheimer's brain, but plaques and tangles are prime suspects.

← GO TO BRAIN TOUR SLIDE 1



11. More about plaques





Plaques form when protein pieces called **beta-amyloid** (BAY-tuh AM-uhloyd) clump together. Beta-amyloid comes from a larger protein found in the fatty membrane surrounding nerve cells.

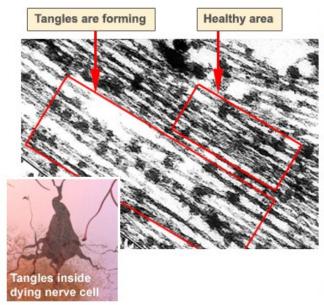
Beta-amyloid is chemically "sticky" and gradually builds up into **plaques**.

The most damaging form of betaamyloid may be **groups of a few pieces** rather than the plaques themselves. The small clumps may block cell-to-cell signaling at synapses. They may also activate immune system cells that trigger inflammation and devour disabled cells.





12. More about tangles





Tangles destroy a vital cell transport system made of proteins. This electron microscope picture shows a cell with some healthy areas and other areas where tangles are forming.

In healthy areas:

- The transport system is organized in orderly parallel strands somewhat like railroad tracks. Food molecules, cell parts and other key materials travel along the "tracks."
- A protein called tau (rhymes with wow) helps the tracks stay straight.

In areas where tangles are forming:

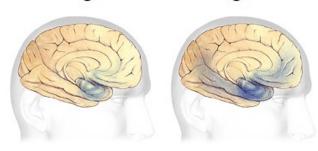
- Tau collapses into twisted strands called tangles
- The tracks can no longer stay straight. They fall apart and disintegrate.
- Nutrients and other essential supplies can no longer move through the cells, which eventually die.

← GO TO BRAIN TOUR SLIDE 1



13. Progression through the brain







Plaques and tangles (shown in the blue-shaded areas) tend to spread through the cortex in a predictable pattern as Alzheimer's disease progresses.

The rate of progression varies greatly. People with Alzheimer's live an average of eight years, but some people may survive up to 20 years. The course of the disease depends in part on age at diagnosis and whether a person has other health conditions.

- Earliest Alzheimer's changes may begin 20 years or more before diagnosis.
- Mild to moderate Alzheimer's stages - generally last from 2 -10 years.
- Severe Alzheimer's may last from 1 - 5 years.

← GO TO BRAIN TOUR SLIDE 1



14. Earliest Alzheimer's stages



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
- · Thinking and planning

← GO TO BRAIN TOUR SLIDE 1



NEXT →

15. Mild to moderate Alzheimer's





In mild to moderate stages, brain regions important in **memory** and **thinking and planning** develop more plaques and tangles than were present in early stages. As a result, individuals develop problems with memory or thinking serious enough to interfere with work or social life. They may also get confused and have trouble handling money, expressing themselves and organizing their thoughts. Many people with Alzheimer's are first diagnosed in these stages.

Plaques and tangles also spread to areas involved in:

- Speaking and understanding speech
- Your sense of where your body is in relation to objects around you

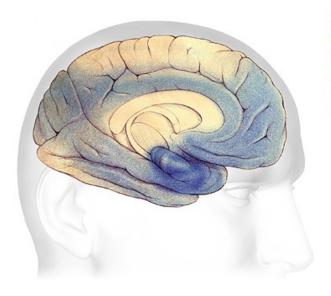
As Alzheimer's progresses, individuals may experience changes in personality and behavior and have trouble recognizing friends and family members.

← GO TO BRAIN TOUR SLIDE 1



16. Severe Alzheimer's disease





In advanced Alzheimer's disease, most of the cortex is seriously damaged. The brain shrinks dramatically due to widespread cell death. Individuals lose their ability to communicate, to recognize family and loved ones and to care for themselves.

← GO TO BRAIN TOUR SLIDE 1



Worksheet

How Much Do You Know?

Circle True or False

Please circle True or False to the statements below. Then, throughout the presentation learn more about each statement and find out how much you know about the early detection of Alzheimer's.

1.	Having a "little touch of dementia" is a normal part of aging.	True	False	
2.	If I have memory loss, that means I have Alzheimer's disease or dementia.	True	False	
3.	If Alzheimer's disease runs in your family, genetic testing will tell you wheth	er you	will	
	get Alzheimer's disease, too.	True	False	
4.	There's no point in getting diagnosed, because dementia is not curable or t	reatabl	e. It	
	will just upset my family and me, so there is no reason to do it.	True	False	
5	5. You don't need a complete set of diagnostic tests to know if you have Alzheimer's			
	disease. You can just try a medication for memory loss – if it works, you kn	now.		
		True	False	

INSTRUCTOR'S KEY!!!

How Much Do You Know?

Please circle True or False to the statements below. Then, throughout the presentation learn more about each statement and find out how much you know about the early detection of Alzheimer's.

	Circle True or False		
1.	Having a "little touch of dementia" is a normal part of aging.	True	False
2.	If I have memory loss, that means I have Alzheimer's disease or dementia.	True	False
	If Alzheimer's disease runs in your family, genetic testing will tell you wheth get Alzheimer's disease, too.	ier you True	False
4.	There's no point in getting diagnosed, because dementia is not curable or t	reatab	le. It
	will just upset my family and me, so there is no reason to do it.	True	False
5	. You don't need a complete set of diagnostic tests to know if you have Alzh	eimer	's
	disease. You can just try a medication for memory loss – if it works, you kn	าow.	
		True	False
			False

Evaluation

Know the 10 Signs of Alzheimer's Disease: Evaluation

Thank you for participating in the 10 Signs of Alzheimer's Disease program. As a participant, we value and appreciate your feedback. Please take a moment to answer the following questions.

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
This program increased my understanding of the 10 signs					
of Alzheimer's disease.					
This program taught me how to recognize the difference					
between typical age-related cognitive decline and					
disease.					
This program taught me what to do if I recognize the					
signs of Alzheimer's disease in myself or a loved one.					
This program increased my understanding of the process					
involved in getting a diagnosis.					
This program helped me to understand the benefits of					
early detection of Alzheimer's disease.					

Please check the signs of Alzheimer's disease that you were already aware of <u>before the program</u>, and those that you are aware of now <u>after the program</u>.

	Before	After
Memory loss that disrupts daily life		
Challenges in planning or solving problems		
Difficulty completing familiar tasks		
Confusion with time or place		
Trouble understanding visual images and spatial relationships		
New problems with words in speaking or writing		
Misplacing things and losing the ability to retrace steps		
Decreased or poor judgement		
Withdrawal from work or social activities		
Changes in mood and personality		

Please tell us a little about yourself.

Age:	Gender:	Racial/Ethnic Identity:	Highest Level of Completed Education:
0-25	Female	American Indian/Alaskan Native	High School or less
26-35	Male	Asian/Pacific Islander	2-year degree / technical degree
36-45	Other	Black, not of Hispanic origin	Bachelor's degree
46-55		Latino/Hispanic	Post-Bachelor's degree
56-65		White	
66-75		Other	
75+			

Handouts & Sign in Sheets





Have you noticed any of these warning signs?

Please list any concerns you have and take this sheet with you to the doctor.

Note: This list is for information only and not a substitute for a consultation with a qualified professional.

1. Memory loss that disrupts daily life. One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. What's typical? Sometimes forgetting names or appointments, but remembering them later.
2. Challenges in planning or solving problems. Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before. What's typical? Making occasional errors when balancing a checkbook.
3. Difficulty completing familiar tasks at home, at work or at leisure. People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. What's typical? Occasionally needing help to use the settings on a microwave or to record a television show.
4. Confusion with time or place. People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there. What's typical? Getting confused about the day of the week but figuring it out later.
5. Trouble understanding visual images and spatial relationships. For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection. What's typical? Vision changes related to cataracts.

6. New problems with words in speaking or writing. People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a watch a "hand clock"). What's typical? Sometimes having trouble finding the right word.
7. Misplacing things and losing the ability to retrace steps. A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. What's typical? Misplacing things from time to time, such as a pair of glasses or the remote control.
8. Decreased or poor judgment . People with Alzheimer's may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. What's typical? Making a bad decision once in a while.
9. Withdrawal from work or social activities. A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. What's typical? Sometimes feeling weary of work, family and social obligations.
10. Changes in mood and personality. The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone. What's typical? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

If you have questions about any of these warning signs, the Alzheimer's Association recommends consulting a physician. Early diagnosis provides the best opportunities for treatment, support and future planning.

For more information, go to <u>alz.org/10signs</u> or call 800.272.3900.

This is an official publication of the Alzheimer's Association but may be distributed by unaffiliated organizations or individuals. Such distribution does not constitute an endorsement of these parties or their activities by the Alzheimer's Association.



Importance of Early Detection



"If we could have had a correct diagnosis even two years earlier, it would have given us more time to plan, to do the things that can result in a good quality of life and to accomplish things we always wanted to do that got put off for this reason or that."

- Jay Smith
Wife, Patty, diagnosed
2 years after onset of
symptoms

altheimer's \$\sqrt{\chi}\$ association' 800.272.3900 | alz.org/10signs











Myth vs. Reality



- ► MYTH Having a "little touch of dementia" is a typical part of aging.
- ➤ REALITY As we age, many of our physical capabilities, including memory, diminish.

 But having a harder time remembering some things is very different from having a form of dementia like Alzheimer's disease.

What is Alzheimer's disease?



- ▶ Alzheimer's is a progressive disease of the brain that destroys brain cells, causing problems with memory, thinking and behavior.
- ▶ Dementia is a general term used to describe a decline in cognitive functioning.
- ► Alzheimer's disease is the most common form of dementia.
- ▶ Though some treatments are available to help with symptoms, Alzheimer's is a disease that is eventually fatal.

altheimer's QS association 800.272.3900 | alz.org/10signs

Myth vs. Reality



- ▶ MYTH If I have memory loss, that means I have Alzheimer's disease or dementia.
- ► REALITY Many people have trouble with memory loss, but it does not mean they have Alzheimer's disease. Most do not. It is best to visit a doctor to determine the cause of the memory loss symptoms.

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Risk Factors for Alzheimer's How the Risks Affect You alzheimer's Qb association

Age is the Greatest Risk Factor The primary risk factor is age The incidence is higher in women, largely due to women living longer **Description** **Object** | **Object**

Myth vs. Reality



- ▶ MYTH If Alzheimer's disease runs in your family, genetic testing will tell you whether you will get Alzheimer's disease too.
- REALITY Having a parent or sibling with Alzheimer's disease does increase one's risk of developing the disease, but genetics is not the only risk factor.

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Genetics



- The gene APOE-e4 is linked to greater risk of lateonset Alzheimer's disease
- ► This type of dementia is most common and associated with old age
- It's a good idea to discuss benefits and risks of testing with a physician or genetic counselor
- ► Having this gene will only increase your chance of developing AD it does not predict the disease

Body-Brain Connection





- ► Brain health comes from a healthy body, learning new things, healthy eating and an active social life
- Risk for AD or vascular dementia is increased by a damaged heart or blood vessels
- Diabetes in mid-life can lead to AD decades later
- There is a strong link between serious head injury and risk for dementia

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The 10 Warning Signs alzheimer's Q5 association

Memory changes that disrupt daily life





- Forgetting something recently learned
- ► Asking the same information over and over
- ► Relying on memory aids or family members for things you used to handle alone





Challenges in planning or solving problems





- ▶ Problems developing or following a plan
- ► Problems working with numbers
- Problems following a familiar recipe
- ► Difficulty keeping track of bills
- ► Challenges concentrating
- ► Taking longer than before to do common tasks



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Difficulty completing familiar tasks





- ► Difficulty completing daily tasks
- ► Trouble driving to once-familiar places
- ► Problems managing a budget at work
- ► Difficulty remembering rules of a favorite game



"My biggest challenge" Joyce has a diagnosis of Alzheimer's disease. altheimer's QS association 800.272.3900 | alz.org/10signs

Confusion with time or place





- Losing track of dates, seasons and passage of time
- Forgetting where one is or how one got there



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Trouble understanding visual images and spatial relationships





- ▶ Diminishing ability to track visual surroundings
 - · Difficulty reading
 - · Trouble judging distance
 - · Problems determining color or contrast



New problems with words in speaking or writing





- ▶ Problems following or joining a conversation
- ► Difficulty tracking conversations
 - Stopping in the middle of conversations, unable to continue
 - · Repeating what was already said
- ► Trouble with vocabulary
 - · Difficulty finding the right word
 - · Calling things the wrong name



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"Things aren't coming out right"





Joyce has a diagnosis of Alzheimer's disease.

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Misplacing things and losing the ability to retrace steps





- Putting things in unusual places e.g., wallet in fruit bowl
- ► Having increasing difficulty retracing steps to locate a missing item
- Accusing others of stealing



Decreased or poor judgment





- ► Changes in decision making and judgment
 - ► Poor judgment with money
 - Giving large amounts to telemarketers
 - · Spending more impulsively
 - · Wearing clothing inappropriate to the weather or season



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Withdrawal from work or social activities





- ▶ Withdrawing from
 - Hobbies
 - · Social activities
 - · Work projects
 - Family gatherings
- Losing track of a favorite sports team
- Forgetting how to engage in a favorite hobby
- ► Avoiding social situations



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Changes in mood and personality





- Increasingly displaying signs of:
 - ► Confusion
 - ▶ Suspicion
 - ► Fear
 - Anxiety
 - ► Agitation



What should I do if I see some of the 10 signs?





- ► Talk with people about what you are seeing and thinking
- A visit to the doctor is indicated
- ► Getting the right treatment as soon as possible is crucial

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"Don't be afraid to talk about it"





Susan's sister, Mary Ann, has a diagnosis of Alzheimer's disease.

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Diagnosis: Earlier is **Better** alzheimer's Qb association

Myth vs. Reality



- ► MYTH There's no point in getting diagnosed, because dementia is not curable or treatable. It will just upset my family and me, so why do it?
- ► REALITY Early diagnosis is the only way to get early treatment for any diagnosis.

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It might not be Alzheimer's or dementia at all.



- ► Some detected problems can be treated or reversed
- ► Some can be life-threatening if not detected or treated promptly
- ► It's important not to ignore changes or assume it is Alzheimer's



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Myth vs. Reality



- ▶ MYTH You don't need a complete set of diagnostic tests to know if you have Alzheimer's disease. You can just try a medication for memory loss if it works, you know.
- ▶ **REALITY** Early treatment is best, but you have to know what you're treating. There are many things that can cause memory loss and it is important to be thoroughly assessed.

"Doctors take time to diagnose" Gary has a diagnosis of Alzheimer's disease. alzheimer's \$\frac{1}{2}\$ association' \$2222,3900 | alz.org/10signs

Diagnostic steps



- ► History from patient, close family and/or friends
- ► Physical exam
- ► Mental status exam
- ► Neurological exam
- ► Brain scans



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Physicians' tests can...



- Identify disorders that may cause memory loss, confused thinking, trouble focusing attention or other symptoms similar to dementia.
- ► Possible disorders include:
 - · Anemia or certain vitamin deficiencies
 - · Excess use of alcohol
 - Medication side effects
 - · Certain infections

Other forms of dementia





- ▶ Vascular dementia
- Frontotemporal dementia (FTD)
- Mixed dementia
- Lewy body dementia

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If you do get diagnosed with a dementia... alzheimer's Q5 association

With early diagnosis you can...



...get the maximum benefit from available treatments

- Explore treatments to provide a relief in symptoms
- ► Early treatment may help individuals remain independent longer
- ► Offers opportunity to participate in clinical trials

"Early diagnosis is very important"





Jestene, 75 years old, has a diagnosis of Alzheimer's disease.

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Medications



- Some medications are designed to help relieve some of the symptoms, but none can stop progression
- Cholinesterase inhibitors may temporarily improve or slow down memory loss
- Other medications can help with mood and behavior changes
- ► Talk to doctors about what treatment is best

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With early diagnosis you can...



... have more time to consider and plan for the future

- ► Participate in arranging your own care
 - · Living arrangements
 - · Safety, financial and legal matters
 - Transportation
- ▶Be empowered to make decisions
- ▶ Build the right care team and social network

Plan for the Future

- ► Seek legal advice and services
- ► Identify and complete legal documents
- ► Make plans for medical and treatment decisions
- ► Make plans for finances and property
- ► Name a person to make decisions on your behalf when you no longer can



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Your Chapter's Services ► Care Consultation alzheimer's ► Information and Referral association' ► Support Groups advancing research, enhancing support Education Safety Services altheimer's QL association 800.272.3900 | alz.org/10signs



If you notice signs...



- ► Talk about what's happening
- ► See a doctor
- Find out why it's happening and what to do about it
- ► Follow up on all diagnostic and treatment recommendations
- Follow up with resources from your chapter

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Mimi has a diagnosis of Alzheimer's disease.







1. Three pounds, three parts



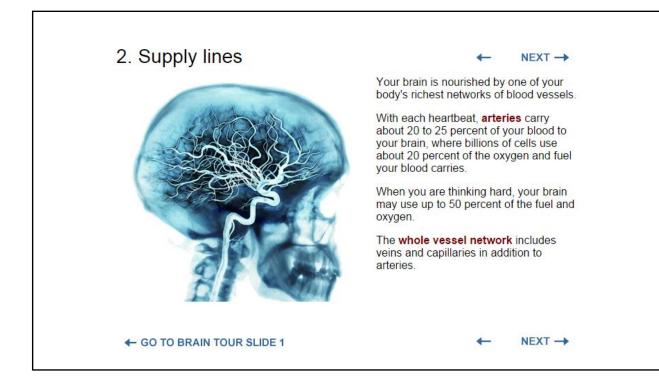


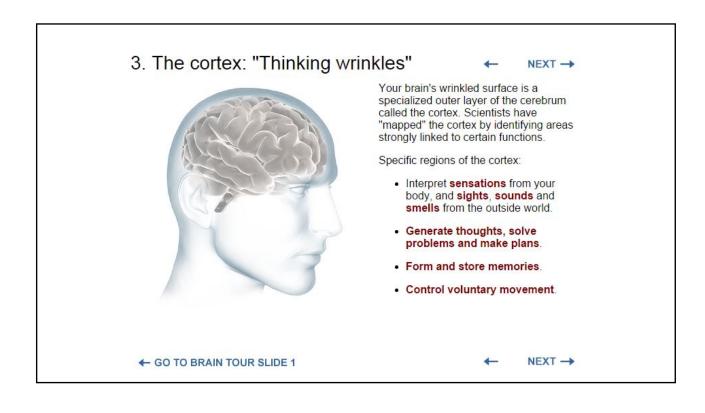
Your brain is your most powerful organ, yet weighs only about three pounds. It has a texture similar to firm jelly.

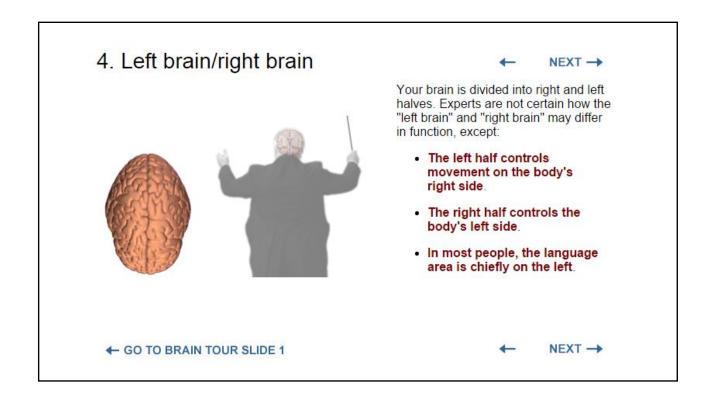
It has three main parts:

- The cerebrum fills up most of your skull. It is involved in remembering, problem solving, thinking, and feeling. It also controls movement.
- The cerebellum sits at the back of your head, under the cerebrum. It controls coordination and balance.
- The brain stem sits beneath your cerebrum in front of your cerebellum. It connects the brain to the spinal cord and controls automatic functions such as breathing, digestion, heart rate and blood pressure.

NEXT →







5. The neuron forest







The real work of your brain goes on in individual cells. An adult brain contains about 100 billion **nerve cells**, or neurons, with **branches** that connect at more than 100 trillion points. Scientists call this dense, branching network a "neuron forest."

Signals traveling through the neuron forest form the basis of memories, thoughts, and feelings.

Neurons are the chief type of cell destroyed by Alzheimer's disease.

← GO TO BRAIN TOUR SLIDE 1

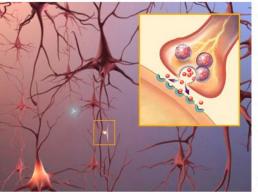


NEXT →

6. Cell signaling







Signals that form memories and thoughts move through an individual nerve cell as a **tiny electrical charge**.

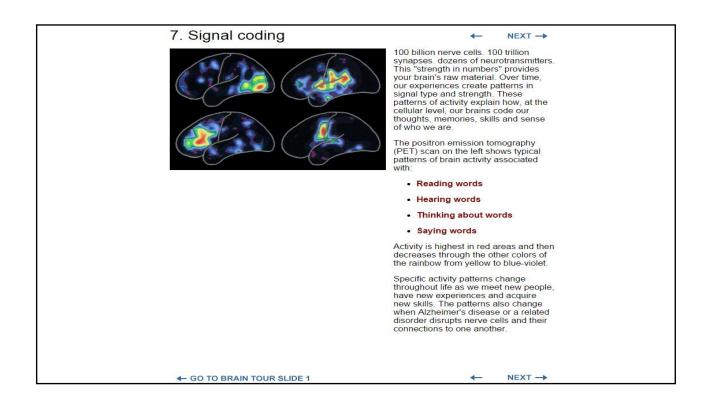
Nerve cells connect to one another at **synapses**. When a charge reaches a synapse, it may trigger release of tiny bursts of chemicals called **neurotransmitters**. The neurotransmitters travel across the synapse, carrying signals to other cells. Scientists have identified dozens of neurotransmitters.

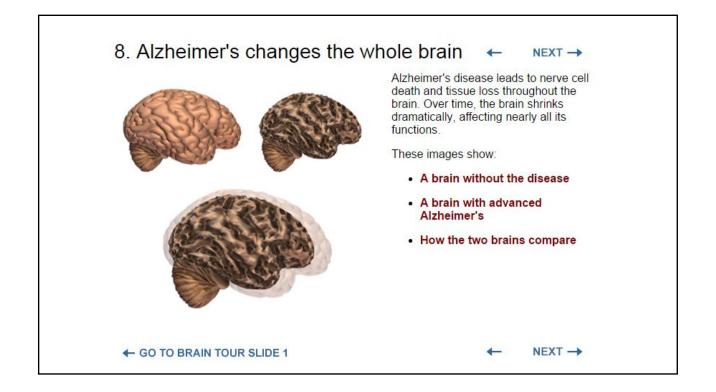
Alzheimer's disease disrupts both the way electrical charges travel within cells and the activity of neurotransmitters.

← GO TO BRAIN TOUR SLIDE 1

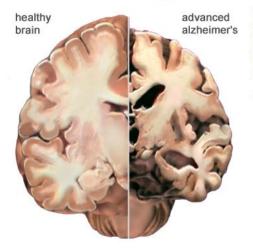


NEXT →





9. More brain changes



← NEXT →

Here is another view of how massive cell loss changes the whole brain in advanced Alzheimer's disease. This slide shows a crosswise "slice" through the middle of the brain between the ears.

In the Alzheimer's brain:

- The cortex shrivels up, damaging areas involved in thinking, planning and remembering.
- Shrinkage is especially severe in the hippocampus, an area of the cortex that plays a key role in formation of new memories.
- Ventricles (fluid-filled spaces within the brain) grow larger.

← GO TO BRAIN TOUR SLIDE 1



NEXT →

10. Under the microscope



← NEXT →

Scientists can also see the terrible effects of Alzheimer's disease when they look at brain tissue under the microscope:

- Alzheimer's tissue has many fewer nerve cells and synapses than a healthy brain.
- Plaques, abnormal clusters of protein fragments, build up between nerve cells.
- Dead and dying nerve cells contain tangles, which are made up of twisted strands of another protein.

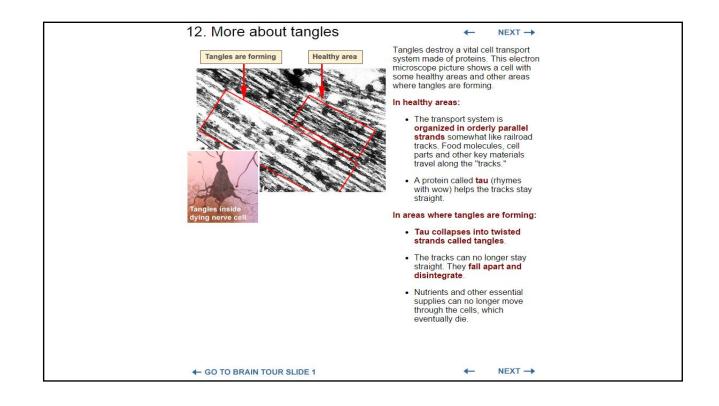
Scientists are not absolutely sure what causes cell death and tissue loss in the Alzheimer's brain, but plaques and tangles are prime suspects.

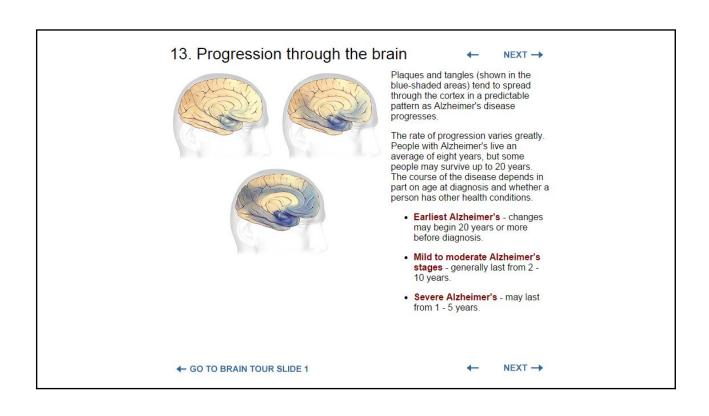
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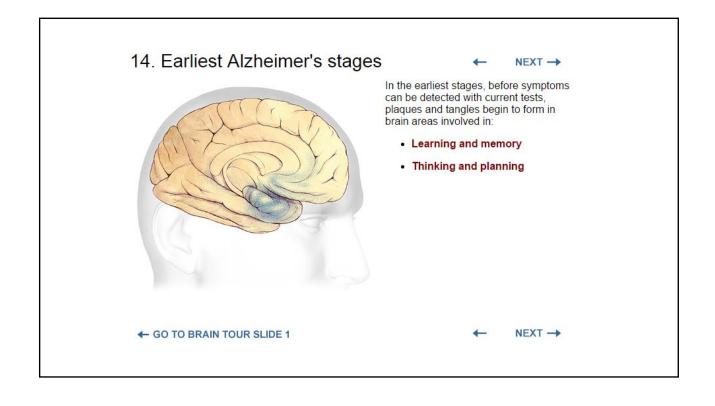


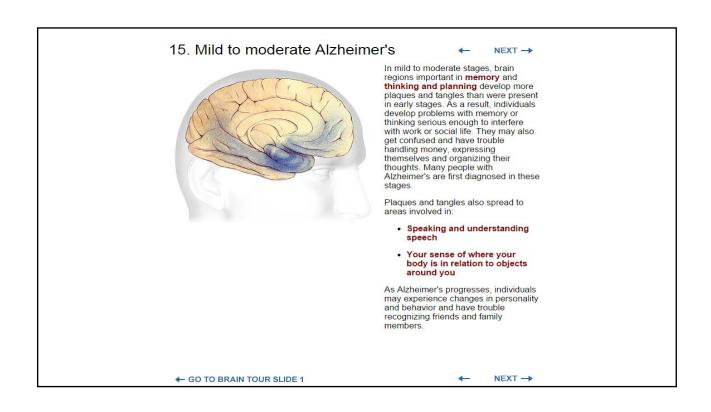
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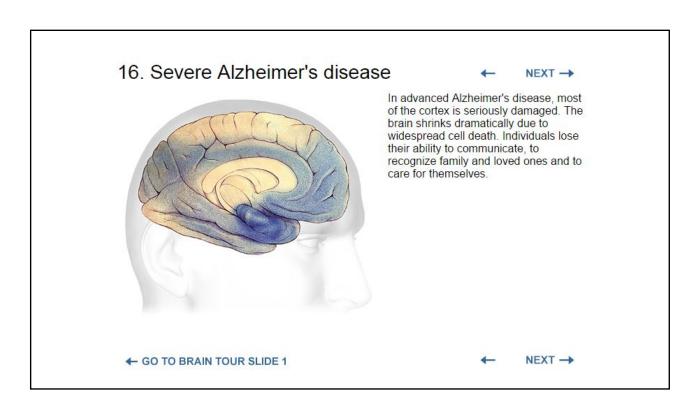












Kansas State University Agricultural Experiment Station and Cooperative Extension Service

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Want to know more from the Alzheimer's Association?

Please write your name and contact information. Then select additional Alzheimer's Association programs you might want to know more about. A representative from the Alzheimer's Association will contact you as soon as possible.

Name	Email	Address/Zip Code*	Telephone Number	Clinical Trials	Advocacy	Walk to End Alzheimer's	Add me to the program e-mail list

^{*}Note: This information will only be used to mail you requested information, educational event information, and a newsletter (if requested). If you are not interested in receiving any of these mailings, please provide us with your zip code so that your attendance in this program can be counted by the Alzheimer's Association and Kansas State Research and Extension.

Resources

Websites:

Websites:				
Organization	Web Address			
Government Aging Website	www.aging.gov			
Alzheimer's Association	www.alz.org			
ALZConnected (Support for caregivers/people with Alzheimer's)	www.alzconnected.org			
Alzheimer's Association e-Learning	www.training.alz.org			
Alzheimer's Foundation of America	www.alzfdn.org			
Alzheimer's Navigator (tools to navigate care needs)	www.alzheimersnavigator.org			
Government Brain Health Initiative	www.acl.gov/Get-Help/BrainHealth/index.aspx & www.brainhealth.gov			
Community Resource Finder	www.communityresourcefinder.org			
Eldercare Locator	www.eldercare.gov			
Family Caregiver Alliance	www.caregiver.org			
Federal Government Caregiver Resource List	www.whitehouseconferenceonaging.gov/happening/reso urces-caregivers.html			
Government Alzheimer's Website	www.alzheimers.gov			
NIA – Alzheimer's Disease Education and Referral Center (ADEAR)	www.nia.nih.gov/alzheimers			
NIA-Funded Alzheimer's Disease Centers (ADCs)	www.nia.nih.gov/alzhiemers/alzhimers-disease-research-centers			
NIH Senior Health: Alzheimer's Disease	www.nihseniorhealth.gov/alzheimersdisease/whatisalzhe imersdisease/01.html			
Medline Plus	www.nlm.nih.gov/medlineplus/alzheimersdisease.html			
Medicare Caregiver Resources	www.medicare.gov/campaigns/caregiver/caregiver.html			
University of Kansas Alzheimer's Disease Center	www.kualzheimer.org			
U.S. Department of Labor – Employed Caregiver Resources	www.dol.gov/whd/regs/compliance/whdfs28.pdf & www.dol.gov/elaws/fmla.htm			
U.S. Department of Veteran's Affairs – Caregiver Support	www.caregiver.va.gov			

Help and Support Lines

	• •
Alzheimer's Association 24-Hour Helpline	1.800.272.3900
NIA Alzheimer's Disease Education And Referral	1.800.438.4380
Center (ADEAR)	
Eldercare Locator	1.800.677.1116
U.S. Department Of Veterans Affairs (VA) Caregiver	1.855.260.3274
Support Line	

10 warning signs of alzheimer's disease

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality



alz.org/10signs

Learn more about the 10 warning signs of Alzheimer's



alz.org/training

Free online workshop: Know the 10 Signs: Early Detection Matters



alz.org/findus

Support groups, education programs and more available in communities nationwide.



800.272.3900

24/7 Helpline — Available all day, every day.

alzheimer's Ω association

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

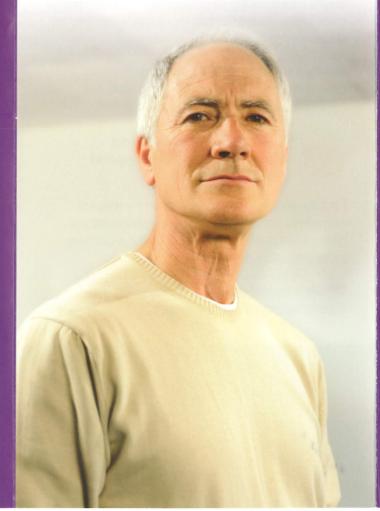
Our vision is a world without Alzheimer's.

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FARLY DETECTION MATTERS



Know the 10 signs

Your memory often changes as you grow older. But memory loss that disrupts daily life is not a typical part of aging. It may be a symptom of dementia. Dementia is a slow decline in memory. thinking and reasoning skills. The most common form of dementia is Alzheimer's (AHLZ-high-merz) disease, a fatal disorder that results in the loss of brain cells and function.

What's the difference?		
Signs of Alzheimer's/ dementia	Typical age-related changes	
Poor judgment and decision making	Making a bad decision once in a while	
Inability to manage a budget	Missing a monthly payment	
Losing track of the date or the season	Forgetting which day it is and remembering later	
Difficulty having a conversation	Sometimes forgetting which word to use	
Misplacing things and being unable to retrace steps to find them	Losing things from time to time	

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alzheimer's 95 association

KNOW the 10 SIGNS

It may be hard to know the difference between age-related changes and the first signs of Alzheimer's disease. Some people may recognize changes in themselves before anyone else notices. Other times, friends and family will be the first to observe changes in memory, behavior or abilities.

To help identify problems early, the Alzheimer's Association® has created a list of warning signs for Alzheimer's and other dementias. Individuals may experience one or more of these in different degrees.



Memory loss that disrupts daily life

One of the most common signs of Alzheimer's disease, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over and increasingly needing to rely on memory aids (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own.

What's a typical age-related change?

Sometimes forgetting names or appointments, but remembering them later.



Challenges in planning or solving problems

Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

What's a typical age-related change?

Making occasional errors when balancing a checkbook.



Difficulty completing familiar tasks at home, at work or at leisure

People with Alzheimer's disease often find it hard to complete daily tasks. Sometimes, they may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.

What's a typical age-related change?

Occasionally needing help to use the settings on a microwave or to record a television show.



Confusion with time or place

People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

What's a typical age-related change?

Getting confused about the day of the week but figuring it out later.



Trouble understanding visual images and spatial relationships

For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast, which may cause problems with driving.

What's a typical age-related change?

Vision changes related to cataracts.







New problems with words in speaking or writing

People with Alzheimer's disease may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a "watch" a "hand-clock").

What's a typical age-related change? Sometimes having trouble finding the right word.



Misplacing things and losing the ability to retrace steps

A person with Alzheimer's may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.

What's a typical age-related change?

Misplacing things from time to time and retracing steps to find them.



Decreased or poor judgment

People with Alzheimer's may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.

What's a typical age-related change? Making a bad decision once in a while.



Withdrawal from work or social activities

A person with Alzheimer's disease may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.

What's a typical age-related change?

Sometimes feeling weary of work, family and social obligations.



Changes in mood and personality

The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

What's a typical age-related change?

Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

Note: Mood changes with age may also be a sign of some other condition. Consult a doctor if you observe any changes.

If you or someone you care about is experiencing any of the 10 warning signs of Alzheimer's disease, please see a doctor to find the cause. Early diagnosis gives you a chance to seek treatment and plan for your future.

The Alzheimer's Association can help.

Visit: alz.org/10signs

Call: 800.272.3900

Learn more: alz.org/training

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the compassion to care, the leadership to conquer

Alzheimer's Disease and Other Dementias

About dementia

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

All types of dementia involve mental decline that:

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

Alzheimer's Disease

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

These symptoms result from damage to the brain's nerve cells. The disease gradually gets worse as more cells are damaged and destroyed. Scientists do not yet know why brain cells malfunction and die, but two prime suspects are abnormal microscopic structures called plaques and tangles.

Vascular Dementia

Many experts consider vascular dementia the second most common type, after Alzheimer's disease. It occurs when clots block blood flow to parts of the brain, depriving nerve cells of food and oxygen. If it develops soon after a single major stroke blocks a large blood vessel, it is sometimes called "post-stroke dementias."

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

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

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

Mixed dementia

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

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

Alzheimer's Disease and Other Dementias

continued

Dementia with Lewy bodies (DLB)

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

Symptoms of DLB include:

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

Parkinson's disease (PD)

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

Frontotemporal dementia (FTD)

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

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

Creutzfeldt-Jakob disease (CJD)

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

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

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

Alzheimer's Disease and Other Dementias

continued

Huntington's disease (HD)

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

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

Wernicke-Korsakoff syndrome

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

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

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

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

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How to Contact the Alzheimer's Association - Heart of America Chapter 1.800.272.3900 • alz.org/kansascity

Main Office 3846 W. 75th Street Prairie Village, KS 66208 913.831.3888 Northeast Kansas Regional Office 3625 SW 29th St. Suite 102 Topeka, KS 66614 785.271.1844 Northwest Missouri Regional Office 10th and Faraon St. Joseph, MO 64501

816.364.4467

Southeast Kansas Regional Office 2601 Gabriel Parsons, KS 67357 620.421.6550 ext. 1794

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Visiting Someone with Alzheimer's Disease

Visiting allows you and the person with Alzheimer's disease to enjoy the company of others. As the caregiver, you can assist family and friends with ideas to make visits meaningful, comfortable, and to use communication techniques, which will enhance their interactions with the person.

Often times people may hesitate to spend time with the person with Alzheimer's because they worry about not knowing what to do or say. Others may not understand the behavior changes that are caused by the disease and feel uncomfortable about visiting.

By working through the concerns of friends and family members, you can continue to give yourself and the person with Alzheimer's an important social outlet. Here are some tips to assist you in having visitors to your home and visiting outside of your home.

Invite visitors to your home

- Don't wait for friends and family to ask if they may stop by for a visit. Instead, take the initiative to contact them and explain that while Alzheimer's disease has changed your lives in some ways, you value their friendship and support and want it to continue. Then suggest a time when they might come over.
- Plan for a successful visit. While the visit certainly doesn't need to be perfect, it should be relaxing and comfortable for everyone.
- Inform visitors about the person's changes in behavior and memory. Mention that the person may fidget or ask the same questions repeatedly.
- Clarify the purpose of the visit. Some people are reluctant to visit because they don't want to be drawn into the responsibilities of caregiving. Be sure to mention that the purpose of the visit is purely social and not to relieve you of caregiving. Make sure that visitors know that their time is a momentary gift of love to the person and a gift of support to you.

- Suggest specific activities such as taking the person to lunch, sitting on the porch, taking a walk, or looking through a photograph album together.
- Remain accessible to visitors. If you're close by, visitors can share specific questions or problems with you. Visitors also may want the chance to talk to you.
- Adjust the nature of the visit to the visitor. Some visitors feel they must do or bring something in order to make the visit worthwhile. You may want to suggest that these visitors bring flowers or special cards.
- Schedule visits when the person's mood and attention are at their best. For example, it may be better for some people with dementia to have morning visits while others may benefit from afternoon visits.
- Be patient with people, and encourage them to be patient with the person with dementia. Even people in such caring professions as social work or pastoral care may have difficulty coming to terms with Alzheimer's. Some people whom you thought you could depend on may avoid you, while others may rally to your side. Try not to take negative reactions personally.

Visiting others' homes

- Prepare your host or hostess. You may want to explain that your visit may be short or that in the middle of it, you may need to take a walk or shift the person's focus to another activity. You may want to bring along a favorite album, book or audiotape to help occupy the person.
- Take pictures of friends and relatives to preserve a happy memory for yourself and the person.

Visiting Someone with Alzheimer's Disease

continued

Visiting the nursing home

- Get acquainted with the staff. Ask questions about special problems or changes involving the person with Alzheimer's. For example, the activity therapist may help provide you with suggestions for new activities of interest to the person.
- Get to know other residents. Your frequent visits to the nursing home bring you into contact with many residents who may not know you personally, but may appreciate your presence.
- Depending on your time constraints, you may want to get involved with other nursing home activities, such as becoming a member of a family council, a group which works with the nursing home staff.
- Prepare friends and family members for nursing home visits. Explain how the person's condition has changed and how long of a visit he or she can handle. Also suggest simple activities such as giving the person a simple gift, putting lotion on his or her hands, or reading a poem or story aloud.
- Ask visitors to leave a card or note when they
 have visited, or provide a guest book in the
 person's room that they can sign. Nursing home
 staff may not remember who has visited in your
 absence. If you know visitors' names and the
 times of their visits you can thank them.
- Time departures when they are engaged in something else. For example, visit before a meal and when they begin eating, say your goodbyes and that you will see them later.
- Time visits on their good times rather than just what is convenient.

Visiting the doctor's office

- Before a doctor visit, advise office staff that the
 person has dementia and their attention span
 may be short and ask if time spent in the waiting
 room can be limited. Ask if you may wait in an
 empty room, ask about parking, distance to the
 building and accessibility of stairs and elevators.
- Be assertive about appointment times. Insist on an appointment during the "best times," for the person based on their routine. If the staff knows the situation, they may be willing to give you an appointment when the office is less crowded or noisy. Consider calling the office before you leave the house to check if the doctor is on time.
- Never leave the person alone in a waiting room.
 Consider taking a third person with you who can drive and help keep the person occupied. It is helpful to offer extra reassurance to the person with Alzheimer's because he or she is away from the familiar environment.
- Even if you plan ahead, you may have to wait longer that expected. Handle the person's hunger by bringing along nutritious snacks. Keep the person busy by playing with a deck of cards, looking at a magazine, or taking a stroll down the hall. Don't worry if the person fidgets or paces. His or her anxiety is normal.
- Use common sense in preparing the person for the visit. Instead of providing an elaborate explanation, simply say, "We're going to see Dr. Jones today." If the person with Alzheimer's objects, avoid getting into an argument by offering a positive suggestion such as, "I need your help in explaining things to the doctor."

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How to Contact the Alzheimer's Association – Heart of America Chapter 1.800.272.3900 • alz.org/kansascity

Main Office 3846 W. 75th Street Prairie Village, KS 66208 913.831.3888 Northeast Kansas Regional Office 3625 SW 29th St. Suite 102 Topeka, KS 66614 785.271.1844

Northwest Missouri Regional Office 10th and Faraon St. Joseph, MO 64501 816.364.4467 Southeast Kansas Regional Office 2601 Gabriel Parsons, KS 67357 620.421.6550 ext. 1794

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You Might Benefit From Talking with the Alzheimer's Association if...

- You or your loved one has been newly diagnosed and you want to learn more about:
 - what the disease means
 - ways to manage
 - telling people
 - connecting with others who are have the disease or are care partners
- Your loved one is experiencing behavior or mood changes
- Your family members all see the situation differently
- You feel like something else needs to happen, but you are unsure what options exist or how to figure out what is needed.
- You would like to talk to other caregivers who are going through the same thing
- You are a community professional and would like to know about education programs the Association offers or need material to share with those you work with about Alzheimer's and other dementias

- You feel heaviness, are overwhelmed or have persistent guilt about your experience as a caregiver of someone with Alzheimer's disease.
- · You want to learn more about:
 - What to expect
 - Strategies to maintain function as long as possible
 - Activities to consider for a person with the disease
- You are concerned about safety issues such as wandering, driving or living alone

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alz.org/care

The Alzheimer's and Dementia Caregiver Center provides reliable information and easy access to tools, such as:

- Alzheimer's Navigator® Assess your needs and create customized action plans.
- ➤ Community Resource Finder Find local resources.
- ▶ ALZConnected® Connect with other caregivers.
- ➤ Care Team Calendar Coordinate caregiving responsibilities among family and friends.
- ➤ Safety Center Access information and tips.



alz.org/findus

Support groups, education programs and more available in communities nationwide.



800.272.3900

24/7 Helpline – Available all day, every day.

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The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's.

800.272.3900 | alz.org[®]

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caregiver stress check

What caregivers need to know to stay healthy



are you stressed?

As a caregiver for a person with Alzheimer's disease or another dementia, you may be so concerned about caring for someone else that you don't realize your own health is at risk. Take our Caregiver Stress Check to help gauge your situation.

Caregiver Stress Check

Do you regularly	
Feel like you have to do it all yourself, and that you should be doing more?	☐ Yes ☐ No
Withdraw from family, friends and activities that you used to enjoy?	□ Yes □ No
Worry that the person you care for is safe?	☐ Yes ☐ No
Feel anxious about money and health care decisions?	☐ Yes ☐ No
Deny the impact of the disease and its effects on your family?	□ Yes □ No
Feel grief or sadness that your relationship with the person isn't what it used to be?	□ Yes □ No
Get frustrated and angry when the person continually repeats things and doesn't seem to listen?	□ Yes □ No
Have health problems that are taking a toll on you?	☐ Yes ☐ No
If you answered "yes" to any question, you	u may be

experiencing caregiver stress. There are things you can do to stay healthy. Make time to consult your doctor, and take

advantage of the full range of helpful services offered by the

Alzheimer's Association®.

we can help.

Alzheimer's Association services and resources include:

- Confidential telephone support, information and referrals to local resources 365 days a year.
- > Care consultation via telephone and online.
- Caregiver support groups.
- > Education programs for families.
- Online information and tools for all those who participate in providing care and making care-related decisions.

Care and support all day, every day.



24/7 Helpline - 800.272.3900

Alzheimer's and Dementia Caregiver Center - alz.org/care

Additional services available nationwide - alz.org/findus

Principles for a Dignified Diagnosis

The first statement of its kind written by people with dementia on the subject of the Alzheimer's disease diagnosis experience.

Talk to me directly, the person with dementia.

I am the person with the disease, and though those close to me will also be affected, I am the person who needs to know first.

Tell the truth.

Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.

Test early.

Helping me get an accurate diagnosis as soon as possible gives me more time to cope, live to my fullest potential and get information about appropriate clinical studies.

Take my concerns seriously, regardless of my age.

Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because of my age. At the same time, don't forget that the disease can also affect people in their 40s, 50s and 60s.

Deliver the news in plain but sensitive language.

My diagnosis may be one of the most important things I ever hear. Please use language that I can understand and be sensitive to how this may make me feel.

Coordinate with other care providers.

I may be seeing more than one specialist — it is important that you talk to my other care providers to ensure you all have the information so that changes can be identified early on and that I don't have to repeat any tests unnecessarily.

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Explain the purpose of different tests and what you hope to learn.

Testing can be very physically and emotionally challenging. It would help me to know the purpose of the test, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

Give me tools for living with this disease.

Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association* and other resources in my community.

Work with me on a plan for healthy living.

Medication may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.

Recognize that I am an individual and the way I experience this disease is unique.

This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.

Alzheimer's is a journey, not a destination.

Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's disease.

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SHOP-14-138 773-10-000



Six out of 10 people with Alzheimer's disease will wander

You can't know when it will happen, but you'll know what to do when it does.

It's common for a person with dementia to wander and become lost. This can happen even in the earliest stages of the disease. Wandering can be dangerous — even life threatening — and the stress of this risk can weigh heavily on caregivers and family.

MedicAlert® + Alzheimer's Association Safe Return® is a 24-hour nationwide emergency response service for individuals with Alzheimer's disease or other dementias who wander or have a medical emergency. We provide 24-hour assistance, no matter when or where the person is reported missing.

How it works

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

Civilians or emergency responders who find the member can call the toll-free number listed on the member's ID jewelry. MedicAlert + Safe Return will notify the person's listed contacts, making sure he or she is returned home.

Cost

\$55 + \$7 shipping and handling fee includes:

- Member's ID jewelry with personalized information and MedicAlert + Safe Return's 24-hour emergency toll-free number.
- » Personalized emergency wallet card.
- » 24-hour emergency response service.
- » Personal health record (PHR).
- » Six Steps to a Safe Return magnet.

An optional caregiver membership is available for \$35. Call or go online to learn more.

Four easy ways to join:

Mail a registration form. Forms are available through the Alzheimer's Association (alz.org/findus).

Call 888.572.8566.

Visit medicalert.org/safereturn and register online.

Fax registration form to 800.863.3429

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10 ways to help a family living with Alzheimer's



- Educate yourself about Alzheimer's disease.
 Learn about its effects and how to respond.
- 2 Stay in touch.
 A card, a call or a visit means a lot and shows you care.
- Be patient.
 Adjusting to an Alzheimer's diagnosis is an ongoing process and each person reacts differently.
- Offer a shoulder to lean on.
 The disease can create stress for the entire family.
 Simply offering your support and friendship is helpful.
- 5 Engage the person with dementia in conversation.

 It's important to involve the person in conversation even when his or her ability to participate becomes more limited.
- 6 Offer to help the family with its to-do list.
 Prepare a meal, run an errand or provide a ride.
- 7 Engage family members in activities.
 Invite them to go on a walk or participate in other activities.
- 8 Offer family members a reprieve.

 Spend time with the person with dementia so family members can go out alone or visit with friends.
- Be flexible.
 Don't get frustrated if your offer for support is not accepted immediately. The family may need time to assess its needs.
- 10 Get involved with the Alzheimer's Association'.

 Show your support by becoming an advocate or participating in Walk to End Alzheimer's and The Longest Day's.

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Understanding is the first step to helping.

People with mild (early-stage) Alzheimer's would like you to know:

- I'm still the same person I was before my diagnosis.
- My independence is important to me; ask me what I'm still comfortable doing and what I may need help with.
- It's important that I stay engaged. Invite me to do activities that we both enjoy.
- Don't make assumptions about me because of my diagnosis. Alzheimer's affects each person differently.
- Take time to ask me how I'm doing. I'm living with a disease, just like cancer or heart disease.
- I can still engage in meaningful conversation.

 Talk directly to me if you want to know how I am.
- Don't pull away. It's OK if you don't know what to do or say. Your friendship and support are important to me.

Family members would like you to know:

- > We need time to adjust to the diagnosis.
- > We want to remain connected with others.
- > We need time for ourselves.
- > We appreciate the small gestures.

Join the fight against Alzheimer's disease.

- > Volunteer at your local Alzheimer's Association office.
- ➤ Participate in Walk to End Alzheimer's and The Longest Day.
- Advocate for more research funding.
- ➤ Sign up for Alzheimer's Association TrialMatch to participate in clinical studies as a healthy volunteer.

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SHOP-15-351 773-10-0005



- Educate yourself about Alzheimer's disease.
 Learn about the disease and what you can expect.
- Allow time to adjust to your diagnosis.

 Take the time you need to feel sad, mourn and grieve your current losses or the expectation of future changes.
- Plan for your future.

 Begin making legal and financial plans after the diagnosis so you can participate in decision making.
- Get support from others like you.
 Meet people living with Alzheimer's by joining a local support group or participating in an online community like ALZConnected".
- Learn about clinical studies. Consider taking part in research that could change the course of this disease and improve the lives of all those it affects.
- Build a care team.
 Assemble family and friends to create a network of help and support. Get started at alz.org/carecalendar.
- 7 Take care of your emotional, physical and spiritual health.
 Identify sources of stress and try to reduce them. Get regular
 medical checkups, eat well, exercise and rest when you can.
- 8 Stay active and engaged.
 Keep your body and mind active with the social and physical activities you've always loved or try something new.
- Fight stigma.
 Tell your story to help dispel the myths and misconceptions about Alzheimer's disease and those who have it.
- Take action.

 Raise your voice as an advocate or raise awareness and funds through events like Walk to End Alzheimer's* and The Longest Day*.

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You are not alone



In communities nationwide, we offer programs and services, including information and referrals, support groups, care consultation, education and safety services.



We're available to talk 24/7 - 800.272.3900

Care consultants are available via our 24/7 Helpline to provide reliable information, referrals and support in more than 170 languages and dialects.



We're online - alz.org/lHaveAlz

Our website includes a section specifically for people living with Alzheimer's disease that offers information and access to tools like ALZConnected® (alzconnected.org), our online community.

You can make a difference



Find volunteer opportunities in your area — alz.org/findus



Sign up for our signature events: Walk To End Alzheimer's (alz.org/walk) and The Longest Day (alz.org/thelongestday)



Advocate for more research funding - alz.org/advocate



Stay informed. Subscribe to our free e-newsletter — alz.org/enews



Participate in clinical studies — alz.org/trialmatch

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