

Purpose of the Speaker's Kit

The impact of Alzheimer's disease is being felt at all levels of the community. Families, service workers, and the general public all need information about the disease. Recognizing the value of educating volunteers, health educators, program directors, and other speakers, the National Institute on Aging's Alzheimer's Disease Education and Referral (ADEAR) Center has created this speaker's kit.

The PowerPoint slideshow, *Alzheimer's Disease: Unraveling the Mystery* is intended for use by speakers addressing lay audiences, such as community groups or clubs, volunteers or prospective volunteers in programs for older people, members of senior citizens' centers, and residents of retirement communities. The presentation is based on the NIA's December 2003 publication of the same name.

We have assembled this kit to help you, the speaker, organize your talk and discuss up-to-date information about Alzheimer's disease with lay audiences. It begins with a brief discussion of the impact of AD on our society. To provide listeners with necessary context, the talk then reviews basic information about AD and how it affects the brain. Following this background, the presentation reviews highlights of ongoing AD research into causes, diagnosis, and treatment, and closes with a description of some current NIA research efforts to improve support for families and other caregivers.

We have prepared a handout that will help your audience contact national resources – such as the ADEAR Center or Eldercare Locator, listed at the end of the slideshow. You may want to prepare your own handouts listing contact information for local resources, including support groups sponsored by organizations such as the Alzheimer's Association. We have also included forms to help your audience get information about participating in clinical trials. If you are from an NIA-sponsored Alzheimer's Disease Center (ADC), please use the form called *ADC Clinical Trial Information Form*. If you are from another organization, please use the form called *For More Information About Participating in Alzheimer's Disease Research Studies* and forward to the ADEAR Center.

Print copies of *Alzheimer's Disease: Unraveling the Mystery* can be ordered from the ADEAR Center by visiting the Web site at www.alzheimers.org, or by calling 1-800-438-4380. The Web site lists many other publications available from the ADEAR Center. When ordering, please allow 2-4 weeks for delivery. Overnight delivery can be arranged by providing your Fed Ex account number to the ADEAR Center. Visit the National Institute on Aging Web site at www.nia.nih.gov. To order NIA publications online, visit www.niapublications.org.

Using the Kit

The Speaker's Kit for *Alzheimer's Disease: Unraveling the Mystery* contains:

- **General guidelines and tips for speaking to lay audiences** to assist you in planning and making your presentation
- **Script** corresponding to the slide set, which consists of: a **description** of each slide, the **script** itself, that is, the information you need to discuss each slide, and **speaker's notes** for some slides, which contain brief supplemental points
- **PowerPoint** file of numbered **slides divided into sections**, with each section introduced by a "Roadmap" slide. Please feel free to reorganize the slides and/or substitute new slides to help address your audience's specific needs. The material is not copyrighted and can be reproduced as needed. Each slide is numbered in the lower right corner. You can edit this number to renumber and reorganize the file and the corresponding "Roadmap" slides. Please provide credit to the National Institute on Aging when using specific slides.
- **Forms, including:**
 - **Audience Feedback** form to receive feedback on your presentation.
 - **2 clinical trials forms:**
 - **ADC Clinical Trial Information** form for use if you are from an NIA-sponsored Alzheimer's Disease Center
 - **For More Information About Participating in Alzheimer's Disease Research Studies** form if you are from another organization. This form is to be forwarded to the ADEAR Center via fax (301-495-3334) or mail (PO Box 8250, Silver Spring, MD 20907). An Information Specialist from the ADEAR Center will contact the person to provide further information about studies in his or her area.
 - **Speaker's Response** form for you to give us *your* comments about improving the kit.

The kit is designed to be flexible and portable. It contains everything you need to organize and present your talk. Depending on the characteristics of your audience and the time

available, you may use all or only some of the slides that are most relevant to your presentation topic. If your time is limited, you may reduce the number of slides and still give a cohesive presentation.

If you have ordered this kit in CD ROM format, please note that the CD also contains a PDF file of the print copy of *Alzheimer's Disease: Unraveling the Mystery* plus a brief animation showing how AD develops, which you may also find useful for certain audiences.

You can reorganize the slides and their corresponding script pages in this kit to follow your own outline. The script for each slide and the speaker's notes are included to help you structure your presentation and anticipate questions from the audience. The CD also contains high- and low-resolution files of the medical illustrations used in the booklet and in the slideshow, which you may also use to customize your presentation.

We hope you will find this speaker's kit a helpful tool as you reach out to your audiences. Our job isn't finished, though, until we hear from you! We need your feedback about this kit. Please take a few minutes after each talk to let us know about your experiences using these materials by completing the speaker's response form.

Getting Organized to Speak Before a Group

Use the checklist below to help you plan ahead for your presentation.

1. Be prepared.

- _____ Confirm the date and time at which you are scheduled to speak, the time you are expected to arrive, and the amount of time allotted for your presentation. Reconfirm with your contact person during the final week before the event.
- _____ Find out the number of people to expect and the interests of the audience, and plan what you will say, and how you may wish to reorganize the Powerpoint slides to match the audience's education, knowledge, and interests. This information will provide the foundation for making a thoughtful, well-organized presentation.
- _____ Have the street address, transportation options, and local directions in advance. Find out where you are likely to find parking and the amount of any parking fees to help ensure that you arrive on time.
- _____ Know the full name of your contact person and all telephone numbers in case of an emergency.
- _____ Bring all the equipment and supplies that you need with you, including a laptop computer equipped with Powerpoint, and projector if using the slideshow, or arrange in advance for someone at the host organization to provide them.

2. Arrive early. Check details before the audience arrives.

- _____ Be at the site ahead of time so that you can check out the meeting location, meet your hosts, set up any equipment you will use, and place materials on resource tables.
- _____ Make sure the equipment is plugged in and works properly, and that the slideshow works.
- _____ Check to see that the laptop computer, projector, screen, lighting, and seating are arranged for the best audience view.
- _____ Bring enough handouts for everyone. Ask host staff to make additional copies available if necessary.

3. Refer questions to others if available and necessary. If you are uncertain of the correct answer to a question, refer the person to other organizations that can help.

- _____ Guide those looking for resources to organizations that make referrals.
- _____ Offer the names of more than one organization if possible. Avoid endorsing one resource organization or local practitioner over another.
- _____ Avoid using the presentation as an opportunity to solicit personal business.

4. Evaluate your experience. Take a few minutes to think about how your talk went.

- _____ How interested was the audience in the information you presented?
- _____ Did you receive questions during your talk? Any comments afterward?
- _____ Use the form at the back of this kit to make suggestions for improvement.

Tips for Speaking to Lay Audiences

1. Use simple language, and avoid technical terms, acronyms, jargon, or unusual words. Speak loudly and clearly. Pause before and after important points.
2. Stand when you speak, so that your audience can see you clearly.
3. Your appearance is important—being well-dressed will improve your confidence, and you will gain respect from your audience.
4. Be yourself—speak in a conversational tone. Emphasize important points, and vary the tone of your voice. Your delivery is as important as the facts you want to convey.
5. If you haven't been introduced, introduce yourself briefly. Don't try to start with a joke—most people are unable to do this well.
6. Relax. Most people are nervous for the first few moments of a talk. Take a few deep breaths before you start and know what you want to say first. Once you get into your talk, you will relax.
7. Make eye contact with each member of the audience. Speak with emotion and sincerity. Smile as often as you can—your audience will respond warmly.
8. Never read your talk. If you must use notes, use an outline to guide you. Look down to see your next point, but then look up again before speaking.
9. Incorporate examples and gestures when possible. Use examples to illustrate your points when you can, as long as they are relevant. Don't digress from your outline or prepared talk unless you're very experienced.
10. Do not be discouraged if someone in the audience appears disinterested or falls asleep. Look, instead, at someone who is actively listening.
11. Never apologize for what you say or what you are about to say.
12. Don't fill in with “um” or “er” or use slang.
13. Leave time for questions. Never tell someone they asked a stupid or irrelevant question. Do not comment that you already covered the issue about which an audience member is asking.

14. Try to end on an upbeat note.
15. Thank your host for inviting you and your audience for listening. Compliment the audience and your host before leaving the podium.
16. Make yourself available for a few moments afterward in case someone has a question to ask privately.

Slide 1. Title

Slide Description:

Alzheimer's Disease: Unraveling the Mystery

Script:

The older population in the United States is increasing dramatically. As of the year 2000, an estimated 35 million people were age 65 and older. Researchers estimate that by 2050, 70 million Americans will be age 65 or older, accounting for 1 in 5 Americans. More than 19 million Americans will be age 85 and older.

The outlook for older people is brighter than ever. The myth that older people always become inactive or experience great loss of mental and physical abilities is being dispelled as researchers identify some of the keys to successful aging.

At the same time, however, we are learning more about a tremendous threat to the health and well-being of all older Americans: Alzheimer's disease and other dementias.

In some respects, Alzheimer's disease is still a mystery. There is much we still don't know about why some people develop it and others don't and how to treat or prevent it. But this mystery is steadily being unraveled and our knowledge is increasing every day.

Slide 2. The Impact of AD

Slide Description:

Photograph of older couple strolling outside;
accompanying text on impact of AD and role of
NIA.

Script:

Once considered a rare disorder, Alzheimer's disease is now seen as a major public health problem because of its impact on millions of older Americans and their families. Research into AD has grown dramatically as a result. Thousands of scientists in laboratories and institutions all over the world are working hard to unravel the secrets of AD and find ways to lessen its impact and perhaps, someday, to prevent it.

The lead agency for AD research at the U.S. Government's agency for medical research – the National Institutes of Health – is the National Institute on Aging.

Slide 3. Alzheimer's Disease: Unraveling the Mystery

Slide Description:

Roadmap slide

- What is AD? (slides 4-6)
- Inside the Human Brain (slides 7-14)
- AD and the Brain (slides 15-22)
- AD Research: Finding New Answers and Asking Better Questions (slides 24-35)
- Improving Support for Families and Other Caregivers (slides 37-39)
- Where to Get Help (slides 40-41)

Script:

This talk will focus on AD and some of the exciting research that's going on right now. Here's what we'll cover. First, we'll look at what AD is and its impact on our society. Then, I'll take you on a quick "walking tour" of the brain and its major parts, which will help you understand the next part of the presentation – what happens in the brain when AD develops.

The second part of this talk will focus on current research into the causes, diagnosis, and treatment of AD as well as research into ways of providing better support for families and other caregivers of people with AD.

At the end, I'll provide information on where you can get more information on AD.

Slide 4. What is AD?

Slide Description:

- Photograph of older woman sitting in chair; accompanying text

Script:

...People came to see her. Sometimes she remembered their names. Sometimes she didn't. Often, she was anxious but she couldn't explain why. The memories came and then they disappeared. Things weren't in the same place as they were yesterday. She worried about her things. Maybe someone had stolen them. It was terrible – she didn't know how to do things anymore....

The gradual slipping away of mind and memory is frightening for a person with AD, as well as for family and friends. Not so long ago, we couldn't do much for someone like this woman. Today, the situation is changing as we learn more and more about AD and how to care for patients and support families.

Formerly called “senility,” we now know that Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys a person's memory and thinking skills. Although the risk of developing AD increases with age, AD is not part of normal aging.

AD is caused by a disease that affects the brain.

Slide 5. What is AD: AD Statistics

Slide Description:

AD statistics on incidence, prevalence, and impact

Script:

AD is the most common cause of dementia among people age 65 and older. Its current and future impact on our society can be seen in these few statistics:

- Scientists estimate that around 4.5 million people now have AD.
- For every 5-year age group beyond 65, the percentage of people with AD doubles.
- By 2050, 13.2 million older Americans are expected to have AD if the current numbers hold and no preventive treatments become available.

Speaker's Notes:

- Researchers recently projected the number of new cases of AD that could occur every year between 1995 and 2050. They estimate that the number will more than double – from 377,000 per year in 1995, to 959,000 per year in 2050.
- Two factors will combine to cause this increase:
 - The fact that AD risk increases as people get older.
 - The growing numbers of older people, especially those over 85.
- The annual number of new cases will increase sharply around 2040, when all baby boomers will be over 65.
- It appears that the number of AD cases may differ across racial and ethnic groups. Finding out more about this issue is an important focus of AD research.

Slide 6. What is AD: AD Statistics

Slide Description:

Statistics on care settings and costs of caring for people with AD.

Script:

People with AD are cared for in many settings, including home, assisted living facilities, nursing homes, and special care units of care facilities. Researchers estimate that the national cost of caring for people with the disease is about \$100 billion per year.

The cost of AD care is more than just financial, of course. Families, friends, and caregivers must also struggle with the emotional and psychological costs of watching their loved one change mentally and physically over time. Caregivers must juggle many responsibilities and adjust to new roles. As the disease gets worse, families may face difficult decisions about long-term care.

Slide 7. Inside the Human Brain

Slide Description:

Roadmap slide

- The Brain's Vital Statistics (slide 8)
- The 3 Main Players (slides 9-11)
- Other Crucial Parts (slide 12)
- The Brain in Action (slide 13)
- Neurons (slide 14)

Script:

A presentation like this wouldn't have been possible 25 years ago. Other than some basics, we knew very little about AD. Today, we know much more about it – what it is, who gets it, how it develops, and what course it follows. We've made major strides in early and accurate diagnosis. We have some promising leads on possible treatments. Recent studies have even focused on ways that people may be able to reduce their risk of developing AD.

Research over the last two decades has deepened our understanding of this devastating disease. It has also greatly expanded our knowledge of brain function in healthy older people.

So, let's start with the healthy brain.

Slide 8. Inside the Human Brain

Slide Description:

Illustration of side view of head with brain visible; selected statistics about the brain.

Script:

To understand AD, it's helpful to know something about the brain and how it functions.

The brain is a remarkable organ. Seemingly without any effort, it allows us to carry out every element of our daily lives. We can breathe, speak, move, see, remember, feel emotions, and make decisions because of the complicated mix of chemical and electrical processes that take place in our brains.

This 3-pound organ, which is about the size of a medium cauliflower, contains about 100 billion nerve cells, or neurons. Neurons are constantly communicating with each other across tiny gaps, called synapses. The brain has about 100 trillion of these synapses.

Slide 9. Inside the Human Brain: The Three Main Players

Slide Description:

Side-view illustration of brain; definition of cerebral hemispheres

Script:

Let's take a closer look at the brain. The cerebral hemispheres – the wrinkled, brown-colored portion of the brain in the illustration – are the largest portion of the brain. They are two symmetrical structures connected by a thick bundle of nerves called the corpus callosum. They have an outer layer of neurons, called the cerebral cortex.

The cerebral hemispheres receive and process all the sensory information we get from the outside world – all the things we see, hear, taste, feel, and smell. They also control voluntary movement. When you choose to stand up at the end of this presentation, thank your cerebral hemispheres!

The cerebral hemispheres also are in charge of regulating our conscious thought, decision-making ability, speech and communication, and other mental activities.

Speaker's Notes:

- This side view shows both the outer layer, the cerebral cortex, as well as some structures that are deep inside the brain, such as the thalamus, hypothalamus, and hippocampus.

Slide 10. Inside the Human Brain: The Three Main Players

Slide Description:

Side-view illustration of brain; definition of cerebellum

Script:

The cerebellum sits underneath the cerebral hemispheres. It's smaller than the cerebral hemispheres, but it has an equally important role. This part of the brain is in charge of the body's balance and coordination. The cerebellum's work allows us to walk smoothly, maintain our balance, and turn around without even thinking about it.

Slide 11. Inside the Human Brain: The Three Main Players

Slide Description:

Side view illustration of brain; description of brain stem

Script:

The third main player is the brain stem, which sits at the base of the brain. It connects the spinal cord with the brain and sends and receives messages from the brain to all parts of the body. Even though it's small, the brain stem's functions are essential to survival because this part of the brain controls all the functions that happen automatically – our heart rate, blood pressure, and breathing. Sleep and dreaming are also controlled by the brain stem.

Slide 12. Inside the Human Brain: Other Crucial Parts

Slide Description:

Side view illustration of brain; definitions of other brain components

Script:

Several other critically important parts lie deep inside the cerebral hemispheres, including:

- The hippocampus, which is important for learning and memory; this part of the brain converts short-term memories into long-term memories for storage in other parts of the brain;
- The thalamus, which receives sensory and limbic information and sends it to the cerebral cortex;
- The hypothalamus, which monitors activities like body temperature and food intake; it controls the body's internal clock;
- The limbic system, which controls emotions and instinctive behavior (includes the hippocampus and parts of the cortex).

Slide 13. Inside the Human Brain: The Brain in Action

Slide Description:

Photographs of activity in various parts of the brain: hearing words, speaking words, seeing words, thinking about words

Script:

As scientists have studied the brain, they've learned that certain parts of the cerebral cortex specialize in particular kinds of mental activity. These PET scans show how this works. The red and yellow areas show that mental activity associated with hearing, for example, takes place in a different part of the cerebral cortex than activity associated with seeing or thinking.

Speaker's Notes:

- New imaging techniques allow scientists to monitor brain function in living people. One of these techniques is positron emission tomography (PET). PET scans use chemicals tagged with a tracer to measure blood flow and glucose metabolism throughout the brain.
- Scientists use PET scans as a research tool to see what happens in the brain when a person is engaged in an activity. When neurons in a brain region become active in response to seeing, hearing, thinking, or some other mental task, blood flow and metabolism* in that region increase. The increased blood flow and metabolism cause that area to “light up” on the PET scan. In essence, a PET scan produces a map of the active brain.

* Metabolism – All the chemical processes that take place in the body. In some metabolic reactions, complex molecules are broken down; in others, simple molecules are combined to make complex compounds.

Slide 14. Inside the Human Brain: Neurons

Slide Description:

Illustration of neurons; text describing structure and function of neurons, and impact of AD on neurons

Script:

Each of the billions of neurons in the brain has a cell body, an axon, and many dendrites. Axons extend out from the cell body and transmit messages to other neurons. Dendrites also branch out from the cell body. They receive messages from the axons of other neurons.

To stay healthy, neurons must carry out three jobs: communicating with each other, carrying out metabolic activities, and repairing themselves.

Alzheimer's disease disrupts all three of these jobs.

Slide 15. AD and the Brain

Slide Description:

Roadmap slide

- Plaques and Tangles (slides 16-18)
- The Changing Brain in AD (slides 19-22)

Script:

Now that we've completed our tour of the brain, let's move on to AD. We'll look first at the two abnormal proteins that are characteristic of the disease, and then see what happens to the brain as AD develops.

Slide 16. AD and the Brain: Plaques and Tangles – The Hallmarks of AD

Slide Description:

Photographs of actual AD plaque and tangle; text defining the two structures

Script:

The brains of people with AD have an abundance of two abnormal structures:

- Beta-amyloid plaques, which are dense deposits of protein and cellular material; these plaques accumulate outside and around nerve cells; and
- Neurofibrillary tangles, which are twisted fibers that build up inside the nerve cell.

Though many older people develop some plaques and tangles, the brains of people with AD have them to a much greater extent.

Speaker's Note

- Scientists have known about plaques and tangles for many years, but recent research has shown much about what they are made of, how they form, and their roles in AD.

Slide 17. AD and the Brain: Beta-amyloid Plaques

Slide Description:

Illustrations of APP molecule being snipped into fragments, forming beta-amyloid plaques; accompanying explanatory text

Script:

Beta-amyloid is formed from amyloid precursor protein, or APP, a protein found in neurons in the brain. As Illustration 1 shows, APP sticks out through the nerve cell membrane – a little like a toothpick through an orange peel.

Certain enzymes cut the APP into fragments of protein, including beta-amyloid. These fragments of beta-amyloid begin to clump together into plaques, eventually disrupting the work of neurons in the hippocampus and other areas of the cerebral cortex. As we saw earlier, these brain regions are important in forming memories and in other mental activities such as thinking and decision-making.

Speaker's Note

- We know that beta-amyloid plaques are an essential feature of AD, but we still don't know whether plaques themselves cause AD or whether they are a by-product of the AD process.

Slide 18. AD and the Brain: Neurofibrillary Tangles

Slide Description:

Illustration of healthy microtubules in a neuron and diseased neuron with abnormal *tau* causing microtubule to disintegrate

Script:

Nerve cells have an internal support structure partly made up of structures called microtubules. These microtubules guide nutrients and other molecules from the body of the cell down to the ends of axon. A special kind of protein, *tau*, makes the microtubules stable.

In AD, *tau* is changed chemically. When this happens, it begins to pair with other threads of *tau* and they become tangled up together into neurofibrillary tangles. This causes the microtubules to disintegrate, collapsing the neuron's transport system.

Scientists think that this process damages the nerve cells' ability to communicate with each other, eventually leading to their death.

Slide 19. AD and the Brain: The Changing Brain in Alzheimer's Disease

Slide Description:

PET scans of normal and AD brain

Script:

No one knows what causes AD to begin, but we do know a lot about what happens in the brain once the disease process takes hold.

These PET scans clearly demonstrate the difference between a normal brain and the brain of a person with AD.

In a PET scan, areas of yellow and red indicate areas of mental activity; shades of blue or black indicate reduced or no activity.

Slide 20. AD and the Brain: Preclinical AD

Slide Description:

Cross-section and side view of brain in preclinical AD

Script:

AD begins in the entorhinal cortex, an area near the hippocampus. It then spreads to the hippocampus. Affected areas begin to shrink and lose function as nerve cells die. These brain changes probably start 10 to 20 years before any visible signs and symptoms.

Although the course of AD isn't the same in every person, symptoms seem to develop in a similar pattern. Memory loss is usually the first visible sign of AD.

Speaker's Notes

- The time from diagnosis to death varies from as little as 3 years (if the person is older than 80 at diagnosis) to 10 or more years (if the person is younger at diagnosis).

Slide 21. AD and the Brain: Mild to Moderate AD

Slide Description:

Cross-section and side view of brain in mild to moderate AD

Script:

As the disease develops, its effects spread through the brain. Brain tissue continues to shrink as neurons stop working and die.

The signs of *mild AD* include memory loss, confusion, trouble handling money, poor judgment, mood changes, and anxiety. It may be several years before family members realize the problem is serious and seek diagnosis.

In the next stage, *moderate AD*, damage has spread further to the areas of the brain that control language, reasoning, sensory processing, and conscious thought. Signs and symptoms become more pronounced, and more intensive supervision and care become necessary. This can be difficult for spouses and family members.

Speaker's Notes

- Most of the signs and symptoms of *mild AD* show themselves in areas related to memory, language, and reasoning. Physical abilities begin to decline only later in the disease. This can lead to a situation in mild AD in which a person seems to be healthy, but is actually having more and more trouble making sense of the world around him or her. People with Alzheimer's disease may refuse to see a physician, denying there is a problem. Other family members may join in their denial.
- Many of the behavioral problems in *moderate AD* occur because the person no longer understands a request or remembers a skill or because the world seems strange and frightening – not because they want to be difficult. A person with AD has no control over the changes that are occurring in his or her brain.

Slide 22. AD and the Brain: Severe AD

Slide Description:

Cross-section and side view of brain in severe AD

Script:

In the last stage of AD, plaques and tangles are widespread throughout the brain, causing extreme shrinkage of brain tissue. Patients cannot recognize family and loved ones or communicate. All sense of self seems to vanish. They are totally dependent on others for their care.

Many people with AD die from aspiration pneumonia. Many caregivers find that hospice care relieves them of the serious stresses of caring for someone who is in the terminal stages of AD. Hospice care offers palliative treatment, which provides comfort and dignity to both patient and caregiver.

Slide 23. AD Research: Finding New Answers and Asking Better Questions

Slide Description:

Roadmap slide:

- The Search for Causes (slides 24-28)
- Diagnosing AD (slides 29-30)
- Clinical Trials (slide 31)
- The Search for Treatments (slides 32-33)
- New NIA Study (slide 34)
- Managing Symptoms (slide 35)

Script:

Current research is helping to provide answers about this complex disease. It is also helping scientists ask better questions about areas that are still unclear.

Investigators are hard at work in a number of areas – the causes of AD, diagnosis, treatment, and symptom management. The next part of this presentation reviews some of this exciting research.

Slide 24. AD Research: The Search for Causes

Slide Description:

Photograph of scientist looking through microscope; accompanying text

Script:

One of the most important parts of unraveling the mystery of AD is understanding what causes the disease. Though we don't have all the answers yet, we now know that AD isn't caused by a single agent.

AD develops when genetic, lifestyle, and environmental factors work together to cause the disease process to start.

- In recent years, scientists have made important discoveries about genetic links to AD. They've also uncovered clues about other factors that may play a role in causing the disease. NIA-funded Alzheimer's Disease Centers (ADCs) across the country are leading the research efforts looking into causes, diagnosis, and treatment of AD.

Slide 25. AD Research: The Search for Causes – Genetic Studies

Slide Description:

Illustration of cell nucleus, chromosome, and DNA strand; accompanying text on genetic linkages to AD

Script:

Very rarely, AD occurs in younger people. This “early-onset” AD occurs between the ages of 30 and 60. It usually runs in families. Researchers have identified mutations in three genes that cause this form of AD.

Most people who develop AD, develop “late-onset” AD. It usually affects people older than 65. Researchers have also found a genetic link to this type of AD. They have identified a risk factor gene that produces a protein called apolipoprotein E, or ApoE. Scientists think that ApoE is involved in forming beta-amyloid plaques and that different forms of ApoE have different effects on a person’s risk of developing AD.

Speaker’s Notes:

- The genes that cause early-onset AD are located on chromosomes 1, 14, and 21.
- ApoE is found in several forms, or alleles:
 - The e2 allele is relatively rare and may provide some protection against AD.
 - The e3 allele is the most common and may have a neutral role in AD.
 - The e4 allele occurs in about 40 percent of people with AD. Studies show that having this allele increases the risk of the disease. Inheriting the e4 allele **doesn’t** mean that a person will definitely develop AD. It’s a risk factor gene

Slide 26. AD Research: The Search for Causes – Late-onset AD Genetics Initiative

Slide Description:

Illustration of researcher and DNA;
accompanying text on a new AD Genetics
Initiative

Script:

The NIA and the Alzheimer's Association have formed a partnership to launch a new study to help narrow the search for genes that may be risk factors for late-onset AD. Under the AD Genetics Study, researchers hope to recruit a total of 1,000 families with 2 or more living siblings with AD and one other living family member with or without AD. If you want to help with this important new study to find late-onset AD risk factor genes, contact, by e-mail: alzstudy@iupui.edu or Web site: www.ncrad.org. A number of NIA-funded Alzheimer's Disease Centers across the country are participating in this study.

Slide 27. AD Research: The Search for Causes – Studies at the Cellular and Molecular Level

Slide Description:

Illustration of cell membrane and free radical; accompanying text about other potential AD risk factors

Script:

In addition to conducting genetics research, scientists are investigating other factors that may influence a person's risk of developing AD.

- One promising area relates to a longstanding theory of aging. This theory suggests that over time, damage from a kind of molecule called a free radical can build up in neurons, causing a loss in function. This damage is called oxidative damage.
- Another active area of research is looking at links between cardiovascular disease and AD. Several studies have shown that an elevated level of an amino acid called homocysteine is associated with increased AD risk. A high homocysteine level also is a risk factor for heart disease.
- In addition, scientists are looking at the cells involved in inflammation and strokes in certain regions of the brain as possible AD risk factors.

Speaker's Notes:

- Clinical trials are underway to see whether certain compounds that affect these factors can reduce AD risk. For example, investigators are studying whether anti-oxidants from dietary supplements may help control free radicals, and whether folic acid and vitamins B6 and B12, which reduce homocysteine levels, can reduce AD risk. They are also studying how reducing inflammation may affect the progress of AD.

Slide 28. AD Research: The Search for Causes – Epidemiologic Studies

Slide Description:

Photographs of nun and priest; accompanying text describing ongoing epidemiologic studies in religious communities

Script:

In another crucial area of AD research, scientists are studying groups of people in hopes of revealing clues to its origins. This type of research is called epidemiologic research.

The NIA is currently funding epidemiologic studies in a variety of different groups. Two of the studies focus on religious communities. The priests, nuns, and brothers in these studies have annual exams that test their physical and mental health. Many participants have also agreed to donate their brains after death.

This exciting research has already had some tantalizing findings:

- Participants who frequently engaged in activities that involve information processing – such as reading, going to museums, and doing puzzle games – were associated with a lower risk of developing AD than did those who did the activities less frequently.
- Many of the nuns whose brain tissue showed significant signs of AD had writings from early adult life with low grammatical complexity and low density of ideas.

The reasons for these findings aren't entirely clear yet, but it may be that mentally stimulating activities are associated with protection against the factors that lead to AD.

Slide 29. AD Research: Diagnosing AD

Slide Description:

Photograph of older woman; accompanying text about importance of early diagnosis

Script:

A diagnosis of Alzheimer's disease can be confirmed only through autopsy, when a physician can actually examine the brain tissue for signs of the disease. However, experienced physicians in specialized AD centers can now diagnose AD with up to 90 percent accuracy.

Early diagnosis has several important advantages:

- Doctors can rule out other conditions.
- If it is AD, families have more time to develop strategies for coping with the disease and to plan for the future, and can include the patient in the discussion.
- Treatments can start earlier, when they may be more effective.

Early diagnosis also helps scientists because the development of tests that can reveal what is happening in the brain in the earliest stages of AD will help them learn more about the causes and development of the disease.

Slide 30. AD Research: Diagnosing AD

Slide Description:

Photograph of person having an MRI;
accompanying text listing diagnostic tools

Script:

Physicians use a number of tools to help them diagnose AD accurately:

- A detailed history of the person's past and present medical condition and a description of how and when symptoms developed.
- Information from family members or close friends about how the person's behavior and personality have changed.
- Physical and neurological examinations and lab tests to determine mental function and identify possible non-AD causes of the problem.
- Q&A tests or other tasks that measure memory, language skills, math ability, and other tests of mental ability; these help indicate what kinds of changes in brain function are occurring.
- Diagnostic tools, such as MRIs and CT scans, which can reveal changes in the brain's structure and function that indicate early AD. In research settings, PET scans are being used to help diagnose AD.

Slide 31. AD Research: Clinical Trials

Slide Description:

Photographs of couple talking with scientist and woman taking a neuropsychological test

Script:

Clinical trials, or studies in people, are the primary way that researchers find out whether a promising treatment is safe and effective. Some trials examine approved drugs to see if they can be used for other purposes. Other trials look at brand new compounds to see if they can help improve cognitive function or slow the progression of the disease.

Participating in a clinical trial is a big step for people with AD and their families. That's why physicians and clinical trials staff spend lots of time talking with participants about what's involved in participating and all the pros and cons.

Many families find that the biggest benefit of being part of a clinical trial is the regular contact with the study team. These visits mean that a person can get state-of-the art AD care and the family can talk on an ongoing basis with experts in AD. These experts have lots of practical experience and a broad perspective on the disease. They can provide advice on the emotional and physical aspects of AD, provide suggestions on coping with the disease, and share information about support groups and other resources.

Speaker's Notes:

- For some years, NIH has made a big effort to improve the diversity of its research participants, and to reach out to groups who traditionally have not participated in clinical trials.
- Increasing the number of older African-Americans, Asians, and Latino participants in clinical trials is a priority. Cultural or language barriers often prevent people in minority groups and their families from going to a

memory clinic or seeking a diagnosis. As a result, clinical trials staff often work with local churches, social service agencies, and other community groups to find recruitment strategies that each culture will be comfortable with.

Slide 32. AD Research: The Search for Treatments

Slide Description:

Text on current drug treatments for AD and on current treatment research; photograph of syringe

Script:

Three drugs are currently approved and used to treat *mild to moderate* AD: Aricept, Exelon, Reminyl. The U.S. Food and Drug Administration has recently approved a fourth drug for the treatment of *moderate to severe* AD. This drug is called Namenda. These drugs may help improve patients' ability to carry out activities for up to a year or so, but they do not stop or reverse AD.

Many scientists are working intensely to develop other compounds that might be useful in treating AD. One of the most exciting recent efforts involved the development of a vaccine. An early clinical trial had to be stopped because of side effects in some participants, but the investigators gained much valuable information in the process. This area of research is still continuing.

Speaker's Note:

- The first drug approved to treat AD was Cognex. This drug is no longer actively marketed by the manufacturer. Side effects of the other medications are considered minimal, and may include nausea, vomiting, diarrhea, or weight loss.

Slide 33. AD Research: The Search for Treatments

Slide Description:

Text on current drug treatments for AD and on current treatment research; photograph of researcher

Script:

Other compounds are being investigated for their potential to slow the progress of AD, delay its onset, or prevent it altogether. These include:

- cholesterol-lowering drugs called statins
- anti-oxidants (vitamins) and folic acid
- anti-inflammatory drugs
- substances that prevent formation of beta-amyloid plaques
- nerve growth factor to keep neurons healthy

Slide 34. AD Research: New NIA Study

Slide Description:

Text on new NIA research partnership;
photograph of researcher

Script:

The NIA is launching a new research partnership, called the Neuroimaging and Biomarkers of AD Initiative, to study how the brain changes in Mild Cognitive Impairment (MCI) and AD and to find biomarkers of AD that could be used to shorten clinical trials.

- Using MRIs and PET scans conducted at regular intervals, researchers hope to learn precisely when and where in the brain problems occur.
- Researchers will also examine blood samples, cerebrospinal fluid, and possibly urine, to check for higher levels of abnormal substances that could be considered “biomarkers” of AD.

Slide 35. AD Research: Managing Symptoms

Slide Description:

Photograph of seated man in bathrobe;
accompanying text about research into drugs for
managing symptoms

Script:

As AD gradually erodes memory and mental abilities, it also begins to change a person's emotions and personality. Over the course of the disease, most people – between 70% to 90% – eventually develop some behavioral symptoms, including sleeplessness, wandering and pacing, aggression, agitation, anger, depression, and hallucinations and delusions. These behaviors may become worse as the day comes to an end, or during daily routines such as bathing.

Most experts advise caregivers to try a variety of techniques to manage troublesome behaviors and only prescribe drugs when the behavior has become too difficult for the caregiver to handle. Symptoms are one of the hardest aspects of the disease for family and caregivers to deal with. Researchers are slowly learning more about why they occur and are studying new treatments – drug and non-drug – to deal with them. These treatments include:

- beta adrenergic blockers
- anti-seizure medications
- cholinesterase inhibitors
- antipsychotic drugs
- antidepressants

Speaker's Notes:

Our growing understanding of what happens in the brain of a person with AD is helping to provide explanations for bizarre or distressing behaviors:

- Feelings of responsibility toward a long-ago night job resurface and compel a woman to get up in the night, get dressed, and leave the house.
- A person may angrily refuse to take a bath or get dressed because he does not understand what a caregiver has asked him to do. The anger is a mask for confusion and anxiety.
- Taking off clothes may seem reasonable to a person with AD who feels hot and doesn't understand or remember that undressing in public is not acceptable.
- Constantly following a trusted and loved spouse or caregiver may be the only source of security to a person who feels that the world around him or her is unknown and frightening.
- Caregivers are encouraged to adopt strategies to manage the person's behavior, such as diverting attention away from the source of distress, going for a walk, listening to soothing music, creating tasks like sorting clothes or weeding, and reminiscing with a photo album.
- Some general tips for caregivers to try in responding to challenging behaviors include:
 - Stay calm and be understanding.
 - Be patient and flexible.
 - Don't argue or try to convince.
 - Acknowledge requests and respond to them.
 - Try not to take behaviors personally.
 - Give yourself a break and don't be too hard on yourself.
 - Accept the behavior as a reality of the disease and try to work through it. Remember: it's the disease talking, not your loved one.

Slide 36. Improving Support for Families and Other Caregivers

Slide Description:

Roadmap slide:

- Who are the AD Caregivers? (slide 37)
- Demands of Caregiving (slide 38)
- Technology and Caregiving (slide 39)
- National Resources for Caregivers (slide 40)
- How to contact the ADEAR Center (slide 41)

Script:

Perhaps one of the greatest costs of AD is the physical and emotional toll on family, caregivers, and friends. Changes in the loved one and the constant caregiving duties can be both hard to bear and rewarding.

Research on caregiver support is still in the early stages. Even so, we've already learned a lot about the unique aspects of caregivers' personalities, situations, and needs for support. The next few slides provide some insights into this new knowledge.

Slide 37. Support for Caregivers: Who Are the AD Caregivers?

Slide Description:

Photographs of people with AD and family members

Script:

Caregivers vary both as individuals and collectively, depending on the culture and ethnic groups with whom they identify. Most primary caregivers are family members:

- Not surprisingly, spouses are the largest group of caregivers. Most are older and may be dealing with their own health problems in addition to caring for the person with AD.
- Daughters are the second largest group of caregivers. Many have families of their own. Juggling two sets of responsibilities can be hard for these members of the “sandwich” generation.
- Sons and daughters-in-law also frequently shoulder caregiving responsibilities.
- Other family members, too, are involved. Brothers, sisters, and grandchildren may have unique needs for caregiving support.

Many other people participate in the care of those with AD. Friends, neighbors, work colleagues, and faith community members often help to care for the person with AD. They also play essential roles in supporting the primary caregivers.

Slide 38. Support for Caregivers: Demands of Caregiving

Slide Description:

Photographs of couple with caregiver and of caregiver support group

Script:

Studies have shown that caregivers of people with AD and other dementias spend significantly more time on caregiving tasks than do caregivers of people with other diseases.

These studies also show that caregiving imposes a significant psychological and physical burden on families. Peer support programs that link caregivers with trained volunteers can help.

Other research has confirmed that the information and problem-solving needs of caregivers evolve over time as the person with AD changes. Support programs can respond by offering services and information geared to the different stages of AD.

Slide 39. Support for Caregivers: Technology and Caregiving

Slide Description:

Photograph of woman at computer station;
accompanying text

Script:

Support groups have always been an important feature of AD caregiver programs. But these groups have drawbacks. The participant must arrange care for the person with AD. The timing of the group may not coincide with the time that the participant needs advice or wants to express feelings. Some people are uncomfortable sharing in a public setting. Members of certain ethnic groups may be especially reluctant to join a support group.

Fortunately, help is on the way. In one of the most exciting new areas of research, investigators are exploring ways to harness the power of the Internet to help caregivers. These studies are examining how computers can provide information and support through:

- Computer-based bulletin boards
- Chat rooms
- Q&A modules
- Medical advice forums

These computer-based support systems have become very popular because they reach many people at once, they provide privacy and convenience, and they are available around the clock.

Slide 40. National Support for Caregivers

Slide Description:

Web pages for the Alzheimer's Association and the Federal Eldercare Locator Service

Script:

Alzheimer's Association

Local chapters provide referrals to area resources and services, and sponsor the Safe Return Program, support groups, and educational programs:

1-800-272-3900

www.alz.org

Eldercare Locator

Nationwide service of the Federal Government helps caregivers locate local support and resources:

1-800-677-1116

www.eldercare.gov

Slide 41. ADEAR Center

Slide Description:

Alzheimer's Disease Education and Referral (ADEAR) Center

1-800-438-4380

www.alzheimers.org

Script:

The Alzheimer's Disease Education and Referral (ADEAR) Center is a service of the National Institute on Aging (NIA). The Center is a source of information and referrals for health and social service professionals, people with Alzheimer's disease and their families, and the general public.

Speaker's Notes:

- The Center produces and distributes a variety of publications about the disease. Information specialists are available to answer questions about Alzheimer's disease through a toll-free telephone line and through e-mail. The Center's Web site provides comprehensive information about AD. Publications can be ordered via the Web site as well.
- You can also contact the Center if you are interested in participating in clinical trials or donating your brain for Alzheimer's disease research. The NIA needs healthy people, as well as people with Alzheimer's disease and other dementias, to serve as volunteers.
- For a list of the NIA-funded Alzheimer's Disease Centers located throughout the U.S., contact the ADEAR Center.

Slide List

1. Title
2. The Impact of AD
3. Alzheimer's Disease: Unraveling the Mystery
4. What is AD?
5. What is AD: AD Statistics
6. What is AD: AD Statistics (continued)
7. Inside the Human Brain
8. Inside the Human Brain (continued)
9. Inside the Human Brain: The Three Main Players
10. Inside the Human Brain: The Three Main Players (continued)
11. Inside the Human Brain: The Three Main Players (continued)
12. Inside the Human Brain: Other Crucial Parts
13. Inside the Human Brain: The Brain in Action
14. Inside the Human Brain: Neurons
15. AD and the Brain
16. AD and the Brain: Plaques and Tangles –The Hallmarks of AD
17. AD and the Brain: Beta-amyloid Plaques
18. AD and the Brain: Neurofibrillary Tangles
19. AD and the Brain: The Changing Brain in Alzheimer's Disease
20. AD and the Brain: Preclinical AD
21. AD and the Brain: Mild to Moderate AD
22. AD and the Brain: Severe AD
23. AD Research: Finding New Answers and Asking Better Questions
24. AD Research: The Search for Causes
25. AD Research: The Search for Causes – Genetic Studies
26. AD Research: Late-onset AD Genetics Initiative
27. AD Research: The Search for Causes – Studies at the Cellular and Molecular Level
28. AD Research: The Search for Causes – Epidemiologic Studies
29. AD Research: Diagnosing AD
30. AD Research: Diagnosing AD (continued)
31. AD Research: Clinical Trials
32. AD Research: The Search for Treatments
33. AD Research: The Search for Treatments
34. AD Research: New NIA Study
35. AD Research: Managing Symptoms
36. Improving Support for Families and Other Caregivers
37. Support for Caregivers: Who Are the AD Caregivers?
38. Support for Caregivers: Demands of Caregiving
39. Support for Caregivers: Technology and Caregiving
40. National Support for Caregivers
41. ADEAR Center Contact Information

National Resources

- **The Alzheimer's Disease Education and Referral (ADEAR) Center** is a service of the National Institute on Aging (NIA). The Center provides information, referrals, and publications for health and social service professionals, people with Alzheimer's disease and their families, and the general public. Information specialists answer questions, refer callers to NIA-funded Alzheimer's Disease Centers located throughout the U.S., and provide information about AD research and current studies.

Alzheimer's Disease Education and Referral (ADEAR) Center
P.O. Box 8250
Silver Spring, MD 20907
Telephone: 1-800-438-4380 (toll-free)
Web site: www.alzheimers.org
Clinical trials database: www.alzheimers.org/trials
E-mail: adear@alzheimers.org

- **The Alzheimer's Association** is a private, non-profit, national organization with many local chapters across the country. These chapters provide referrals to area resources and services, and sponsor the Safe Return Program, support groups, and educational programs.

Alzheimer's Association
225 N. Michigan Avenue, Suite 1700
Chicago, IL 60601
Telephone: 1-800-272-3900
Web site: www.alz.org
E-mail: info@alz.org

- **The Eldercare Locator** is a nationwide service of the Federal Government that helps caregivers locate local support and resources.

The Eldercare Locator
Telephone: 1-800-677-1116
Web site: www.eldercare.gov
E-mail: eldercare_locator@aoa.gov

- The National Library of Medicine provides information about clinical trials and opportunities to participate in the evaluation of new treatments and drugs.

Web site: www.clinicaltrials.gov

Meeting Date: _____

Location: _____

Audience Feedback Form

Please take a few minutes to give your feedback on this presentation. It will help us to serve you and others better in future programs. Thank you.

1) **This presentation was:** (rate the program by circling a number on each scale below)

	Not at all		Extremely		
Helpful	1	2	3	4	5
Easy to understand	1	2	3	4	5
Well-organized	1	2	3	4	5

2) **This presentation increased my understanding of Alzheimer's disease:**

Strongly disagree

Strongly Agree

1 2 3 4 5

3) **As a result of this presentation, I would consider participating in a research study:**

Strongly disagree

Strongly Agree

1 2 3 4 5

4) **Why did you attend this presentation?**

____ Interested in the subject

____ Think a loved one might have AD

____ Concerned about memory loss

____ Other: _____

5) **How did you hear about this presentation?**

____ Newspaper

____ Other publication

____ Radio

____ Friend

____ TV

____ Organization

____ Other: _____

6) **Do you have questions about Alzheimer's disease that were not answered ?**

7) **Other comments?**

ADC Clinical Trial Information Form

Research is our best hope for a world without AD. To continue our progress toward understanding and one day ending AD, researchers need all kinds of volunteers to participate in clinical trials, including people to serve as normal volunteers, as well as people with AD and other dementias.

If you would like information about participating in AD studies or clinical trials, please print your name, address, telephone number, and e-mail below and return this page to the speaker. A staff member from the Alzheimer's Disease Center in your area will contact you about current volunteer opportunities.

NAME: _____

ADDRESS: _____

TELEPHONE: _____

E-MAIL: _____

For More Information About Participating in Alzheimer's Disease Research Studies

Research is our best hope for a world without AD. To continue our progress toward understanding and one day ending AD, researchers need all kinds of volunteers to participate in clinical trials, including people to serve as normal volunteers, as well as people with AD and other dementias.

If you would like information about participating in AD studies or clinical trials, please print your name, address, telephone number, and e-mail below and return this page to the speaker. Your contact information will be forwarded to the NIA ADEAR Center, and an Information Specialist will contact you to give you further information about studies in your area.

NAME: _____

ADDRESS: _____

TELEPHONE: _____

E-MAIL: _____

*Speaker: Please forward this form to the **ADEAR Center** via fax (301/495-3334) or mail (PO Box 8250, Silver Spring, MD 20907). Thanks!*

Speaker's Response Form

Name of meeting _____

Type of audience _____

Location of meeting _____

Approximate number in attendance _____

Are these materials well-organized for your purposes? If not, please explain.

Was this kit helpful to you in preparing your talk? If not, please explain.

Are the materials easy to use?

Do you think that the text slides were clear to the audience? Did you receive any questions that indicated that one or more slides are unclear? What were they?

Is there additional information you would have liked to have on the slides?

What questions from the audience were you unable to answer or did you have trouble answering?

What would improve this kit and its contents?

Thank you for responding to these questions. Your feedback is valuable to us!
Please send a completed copy of this form to: Alzheimer's Disease Education and Referral Center
Fax: 301-495-3334 Mail: P.O. Box 8250, Silver Spring, MD 20907