



Alzheimer's Awareness Family Night

HANDOUTS AND RESOURCES

SESSION #1:

The Importance of an Early Diagnosis and Understanding the Stages of Alzheimer's Disease

Welcome to Alzheimer's Awareness Family Night. Today we are going to discuss:

- What is the difference between dementia and Alzheimer's disease?
- How is the progression of Alzheimer's disease measured?
- How can families and friends support loved ones with Alzheimer's disease throughout the disease process?

We appreciate your participation and look forward to your comments, questions, and suggestions.

Handout #1: Opening Exercise



Session #1:
The Importance of an Early Diagnosis and Understanding the Stages of Alzheimer's Disease

Handout #2: No-Pressure Quiz

Please answer each question to the best of your ability OR leave your quiz paper blank, and fill in the correct answers during our group discussion.

- 1. Which of the following is NOT a part of normal aging?**
 - A. Hearing loss
 - B. Vision challenges
 - C. Severe memory loss
 - D. Mobility challenges
 - E. All of the above
- 2. The two main types of dementia are: reversible dementia and Alzheimer's disease. Is this statement true or false?**
 - A. True
 - B. False
- 3. Dementia is a set of symptoms that can accompany many diseases or conditions. Which of the following are symptoms of dementia?**
 - A. Problems with numbers
 - B. Language deterioration
 - C. Poor judgment and reasoning skills
 - D. B and C only
 - E. All of the above
- 4. There is currently no definitive test to indicate that someone has Alzheimer's disease. Is this statement true or false?**
 - A. True
 - B. False
- 5. Which of the following is NOT a reason that an early diagnosis may be beneficial?**
 - A. Better prescription coverage from most insurance companies
 - B. A chance to benefit from drug treatments that may help to slow the symptoms of the disease
 - C. An opportunity to plan for the future and participate in decisions that can help maximize quality of life and care
 - D. The chance to help oneself and others through participation in a clinical trial
 - E. All of the above

- 6. Most individuals with Alzheimer's disease are capable of which of the following until late into the disease's progression?**
- A. Being social and polite
 - B. Showing pleasure and enjoyment
 - C. Appreciating humor
 - D. A and B only
 - E. All of the above
- 7. Which of the following is something those in the early stage of Alzheimer's disease would likely find challenging?**
- A. Remembering a dentist appointment
 - B. Experiencing joy at a granddaughter's wedding
 - C. Carrying on polite conversations with an old friend
 - D. A and C only
 - E. All of the above
- 8. A person in the middle stage of dementia is not safe living independently. Is this statement true or false?**
- A. True
 - B. False
- 9. Even in the very end stage of Alzheimer's disease, people can enjoy music, gentle hugs and touches, and the company of the people who love them. Is this statement true or false?**
- A. True
 - B. False
- 10. Which of the following describes a way families can be supportive of persons with dementia?**
- A. Helping the person to avoid embarrassing situations
 - B. Finding opportunities for the person to feel useful
 - C. Being patient with the person
 - D. Looking for things to laugh at together
 - E. All of the above

Handout #3: Important Points and Resources

What is normal aging?

Normal aging typically involves:

- Vision challenges
- Hearing loss
- *Slight* memory loss – People need to concentrate harder on remembering names or new information; they are slower in coming up with answers.
- Varying dexterity and mobility issues

What is dementia?

- It is not a disease, but a set of symptoms that can accompany many diseases or conditions, and it gets worse over time, affecting more parts of the brain.
- *Reversible* forms of dementia can be treated and cured. Common causes of (usually) reversible dementias include prolonged dietary deficiencies, adverse reactions to medication, certain infections, operable brain tumors, and depression.
- *Irreversible* forms of dementia are, by definition, currently incurable, but they can be treated.
- Common symptoms of dementia include:
 - Memory loss
 - Difficulty performing familiar tasks
 - Language deterioration
 - Disorientation to time and place
 - Poor judgment and reasoning skills
 - Problems with numbers
 - Loss of initiative

The three most common causes of irreversible dementia are Alzheimer's disease, vascular dementia (formerly called multi-infarct dementia), and dementia with Lewy bodies (DLB). Alzheimer's disease is the most common of these, but many people have a combination.

How is Alzheimer's disease diagnosed?

There is currently no single definitive test to indicate that someone has Alzheimer's disease, which means that most testing is done in order to eliminate other diagnoses. Typical tests ultimately lead to about 90% accuracy and may include:

- A detailed medical and family health history
- A detailed description of symptoms (self-report and from family)
- A mental status evaluation
- A thorough physical examination
- A neurological examination
- Laboratory tests and brain imaging tests
- Psychiatric/psychological evaluations

What are the benefits of an early diagnosis?

- Alzheimer's disease is a frightening diagnosis to face, but many people find relief in knowing exactly what they are dealing with
- The chance to be cured if one has a reversible form of dementia
- A chance to benefit from available drug treatments
- Time to plan for the future and to participate in decisions that can help maximize quality of life and care
- A chance to help oneself and others through participation in a clinical trial

What are common strengths and losses of individuals with AD in the early stage of the disease?

The progression of Alzheimer's disease is usually measured in three stages: early, middle, and late. There are common patterns of progression coinciding with these stages, but they are not universally present. The most important thing to remember is that **each person with AD is a unique individual**, and his progression is based on a unique set of life experiences that may or may not follow the typical patterns outlined here.

People with Alzheimer's disease can perform fewer tasks over time, but they still have all of the characteristics that make each of us uniquely human. For instance, even until very late in the disease process, those with AD tend to be able to do the following in some form:

- Be helpful and active
- Be social and polite
- Show pleasure and enjoyment

- Show affection and compassion
- Express a full range of emotions
- Tap into their sense of humor

In the early stage, people with AD may have trouble with:

- Time and numbers – knowing the date, adding up a golf score, making change, balancing a checkbook, knowing when a recent event happened
- Visual/spatial challenges – finding items in a grocery store, following a map, efficiently loading a dishwasher
- Complex tasks – following a recipe or other written directions
- Memory – remembering names, appointments
- Language – they may have word-finding difficulties or misuse a word
- Judgment – they are an easy mark for unscrupulous salesmen

What are common strengths and losses of individuals with AD in the *middle* stage of the disease?

In the middle stage of AD, people typically have some measure of the same strengths that had in the early stage. But **in the middle stage of AD, a person is not safe living independently.** Here are some common losses:

- Time – The person is often living in a past reality (believing, for example, that she is a young mother) or floating in and out of present reality.
- Visual/spatial challenges – Peripheral vision, proprioception and depth perception deteriorates.
- Complex tasks – Apraxia and agnosia make ordinary self-care tasks increasingly difficult.
- Memory and language continue to deteriorate.
- Judgment – Without a clear sense of time, a person is likely to leave something cooking too long on the stove or forget to turn off a burner.

What are common strengths and losses of individuals with AD in the *late* stage of the disease?

Here are some signs that a person is in the late stage of Alzheimer's disease:

- The person has an abnormal appearance, often with a blank or vacant expression, a tilt to one side when he walks and an unsteady gait.

- Vocabulary is extremely limited or completely unintelligible.
- Vision and proprioception problems increase.
- They become incontinent of bowel and bladder.
- They need assistance with all ADLs (dressing, grooming, bathing).
- They tire easily and may sleep much of the day and night.

Nevertheless, even in the very end stage of the disease, people can enjoy music, gentle hugs and touches, and the company of the people who love them.

How can families be supportive of people with AD in various stages?

Here are a few guidelines:

- Do not underestimate the person. Think of the personality traits, skills, and talents this person was known for before the diagnosis. How can you continue to highlight, nurture and support those?
- As a person's abilities deteriorate, look for the *parts* of the activity that can still be enjoyed.
- Look for what you can simplify, and do so whenever possible.
- As the disease progresses, avoid crowds, noise, and bustle, and provide increasingly longer periods of time to recover from busy events such as a holiday meal.
- Help the person to save face by preventing embarrassing situations.
- Give the person opportunities to feel useful and valued.
- As the world around them becomes increasingly confusing, people with AD are often frightened, frustrated, and embarrassed. Look for ways to draw out their best qualities and to diminish the obstacles they face.
- Give latitude for bad days. We all have them. Be forgiving of evening fatigue and crabbiness; we've all known it.
- Be patient and willing to go slower. Rushing increases confusion (and resistance).
- Look for things you can laugh at together. Humor is our very best coping skill.

Resource List

Here are a few resources for learning more about various forms of dementia, how a diagnosis is made, and what treatments and support services are available:

- The Alzheimer's Disease and Referral (ADEAR) Center produces dozens of free fact sheets in both English and Spanish. Request them by phone 800-438-4380 or print them from the website: <http://www.nia.nih.gov/Alzheimers/Publications/>
- Reach the National Alzheimer's Association helpline 24/7 at 800-272-3900, call 312-335-8700 during normal central time business hours, or check out their website (<http://www.alz.org>) for info on local chapters and publications.
- The Alzheimer's Foundation of America has additional information: 866-232-8484 or <http://www.alzfdn.org>.

There are a number of places you can go to learn more about the stages of Alzheimer's disease and the remaining strengths in people who have it. Here are a few resources:

- www.alzheimer.ca/english/disease/progression-gdscale.htm
- www.alz.org – go to the Alzheimer's disease heading and look under “stages.”
- *Alzheimer's Basic Caregiving and Activities of Daily Living – an ADL Guide for Alzheimer's Care* by Kathy Laenhue (www.wisernow.com © 2006)
- *Alzheimer's Early Stages* by Daniel Kuhn (Hunter House Publishers, Alameda, CA © 2003)
- *Dementia Reconsidered* by Tom Kitwood (Open University Press, Philadelphia. © 1997)

Two excellent resources for learning more about end-of-life issues and helping people with AD to a peaceful death are:

- *The End-of-Life Namaste Care Program for People with Dementia* by Joyce Simard. © 2007. Available from Health Professions Press (www.healthpropress.com or 888-337-8808) or Amazon.
- *Hard Choices for Loving People* by Hank Dunn (a former Hospice chaplain) is an inexpensive booklet (2,000,000 copies sold) available through his website www.hardchoices.com or by phone 571-333-0169.

