



Alzheimer's Awareness Family Night

LEADER'S GUIDE

SESSION #1:

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

Basic Guidelines for Hosting a Family Night

Educating the loved ones of those with Alzheimer's disease can help improve not only their caregiving experience, but the quality of life of those with the disease. To this end, we have created a series of family night sessions designed to assist you in addressing major topic areas related to Alzheimer's disease.

Family nights have two goals:

1. To provide practical information for families and friends of those living with Alzheimer's disease.
2. To help reduce the stress associated with having a loved one with Alzheimer's disease by offering that information in a friendly and supportive atmosphere.

To facilitate the first goal, this packet contains both information for you as the session leader and ready-made handouts for attendees. The second goal may be achieved in a variety of ways, for example:

- Make **invitations** to the family night warm, enticing, and clear, and provide directions and any important details.
- When a potential attendee **responds** to the invitation, be sure the person who answers the phone has a smile in her voice and is well-informed about the event.
- Provide an **atmosphere** that delights the senses. The setting for your meetings should look and smell pleasant, be an appropriate temperature, and offer comfortable seating. Tasty refreshments should also be available for attendees.
- **Welcome** each attendee as he or she arrives. If you have invited other staff, residents or volunteers to help you, make sure they are trained to do the same. Provide easy-to-read **name tags** for everyone.
- **Learn** as much as you can about each attendee's situation *before* the program begins by chatting with them when they arrive, rather than spending that time making last-minute notes or other preparations.
- **Introduce** attendees to one another so that each person feels a part of the group.
- Do your best to **present information with ease and confidence**. Remember that your audience **WANTS** you to succeed. They want to learn new information and come away with tips for being better caregivers, and they will be grateful that you are genuinely interested in their individual needs and experiences.
- Encourage **participation** from attendees by acknowledging their responses and answering additional questions with a positive demeanor.
- **Follow up** by inviting them back to future sessions. Provide them with handouts even if they miss a session. Get back to them with any questions you could not answer initially.
- **Seek attendees' input** about the session, as well as how to improve future sessions.

Room arrangement

If possible, arrange the room in a circle or semi-circular rows so that people can see each other. This automatically adds an element of friendliness. If there are rows, keep them wide. Because many older adults need to get up and move around regularly to prevent stiffness, make sure they feel free to do so – or build breaks and/or stretches into your session.

Using the materials effectively

- Make sure you have enough pens or pencils and that you have made enough copies of handouts for each attendee before everyone arrives.
- When attendees arrive, we suggest you give them only *Handout #1: Opening Exercise* and a pen or pencil. Each session begins with a puzzle, exercise or conversation starter related to the evening's topic that is intended to arouse their curiosity, along with the questions we expect to answer during the session. These activities will always be labeled as "Handout #1: Opening Exercise."
- Once attendees have completed *Handout #1*, and you have offered a brief explanation of its relevance, give each participant a copy of *Handout #2: No-Pressure Quiz*. Remember to keep the introduction of the opening quiz light and humorous. The quiz is not intended to measure attendees' knowledge as much as it is designed to be a vehicle for a discussion of the evening's important topics.
- Wait until the end of the session to pass out *Handout #3: Important Points and Resources*, but let attendees know at the beginning of the session that you will be providing an additional handout before they leave. We want to promote discussion and draw out the experiences and knowledge of the attendees. If they are given the discussion points at the outset, they are less likely to give original thought to the questions, and it is their comments that are most likely to enliven the session.

Using the leader's guide

- Material intended for the session leader only is provided in Arial type.
- Material to be presented to attendees (such as questions to ask or directions to be given) is provided in Times New Roman type.
- Each leader's guide provides a fair amount of detail about session topics. If your time is limited, you may wish to consider incorporating less of this detail.

General instructions for each session

- Begin the session by welcoming the group and introducing yourself and any assistants you have asked to help.
- Try to avoid discussing “housekeeping” issues during the session. Instead, provide information, such as the location of restrooms, on a flip chart so that even late-comers will be informed.
- Posting a session agenda is also recommended and should include any planned breaks. If you are not planning a session break, direct attendees’ attention to the restroom flip chart, and encourage them to ‘get up and go’ anytime. Doing so lends a touch of humor while letting attendees know you realize they are adults who can make their own choices about comfort.
- One of the principles on which this material is based is that those in your audience are the best teachers. Throughout each session, we offer questions to ask attendees. Their answers are likely to vastly enrich each session, provide many concrete examples related to various subtopics, and spark interesting and relevant conversations. Offering attendees a chance to respond to questions, and *then* filling in whatever details they don’t mention is an excellent way to keep attendees involved.
- Practice going through the materials before you begin, not only to become familiar with them but to have a sense of how much time each section will take. Assign a time period – depending upon the total amount of time you have – for each section, and be sure to allot enough time for attendee input and questions related to each section. Do your best to adhere to your planned schedule so you don’t feel rushed. You may opt to offer to stay after the session to discuss the experiences of anyone who didn’t have the opportunity to share during the session.
- Make the material your own. Add your own stories, insights, and creativity as time and topics allow.
- Begin and end on time. This is always appreciated – even by late-comers.
- At the end of the session, create a simple parting ritual: Let attendees know when the group will meet again and what topics will be addressed. Invite them to stay for more refreshments and to visit with each other and with you. Thank them sincerely for their shared insights and their devoted efforts as caregivers.

Training techniques to keep in mind

Dealing with the “gotta-have-an-answer” question

As you lead family nights, you are likely to encounter an attendee who has come to your session for the express purpose of finding an answer to a specific question about a particular situation. Once he has asked the question, there are essentially two ways to answer:

- If the question is relevant to the topic being discussed, give a time limit, which you announce (“This is a complex issue, but we can devote the next three minutes to an answer.”). You may wish to ask for more detail about the situation (What interventions has he tried? What were the results?) When you feel you have the needed detail, ask for input from other members of the audience – they may have terrific ideas. If there is still time, provide any answers of your own as well as you are able.
- If the question is *not* relevant, or if your allotted time has run out, write the question on a post-it note and put it in a “parking lot” –a flip chart, white board, or wall that is reserved for unanswered questions. Tell the person you can’t answer his question now, but that you will be happy to address it either at the end of the session if time allows or after the session.

When you don’t know the answer

When you don’t know the answer to an attendee’s question it’s best to say so, but promise you’ll do your best to find out and follow-up. Once you have found an answer, report back to the person who asked by phone, email or in writing. If it’s important to multiple people, provide the answer to the whole group in your next session.

When one person dominates the session

Often, people don’t realize they are monopolizing a group discussion, but as the session leader, you have a responsibility to remedy the situation. Depending on your personal style, you may choose to be straightforward or subtle in your approach. You can say something direct, such as, “I appreciate your input, Mrs. Jones, *and* now I would like to hear from other members of the group.” (Using “and” instead of “but” validates Mrs. Jones’s input while sending the message that others deserve a turn to speak as well.) A more subtle approach might be to toss a Koosh ball, Nerf ball, or beach ball, and establish that only the person holding the ball can speak. That tends to liven up a session with color and motion, and keeps the discussion spread out. Whatever approach you choose, do your best to encourage active participation among all attendees without allowing one person to control the conversation.

When someone doesn’t participate at all

In any group there is likely to be someone who chooses to simply listen. Respect that choice. If a ball is tossed to him (such as in the approach above), make sure he understands he can pass it to someone else without commenting. At the same time, after the session or during a break, make a point of talking with him to find out if he is finding the session useful or if he has any specific questions. He will appreciate not being put on the spot in front of everyone and will probably give you honest feedback. Often, those who choose to listen are perfectly content, but just don’t wish to speak in front of a group.

Opening Exercise and No-Pressure Quiz

After welcoming attendees to family night, give each person a copy of Handout #1, and ask them to take a moment to look at the puzzle and try to figure out the phrase it represents. Let them know that the phrase is an important one to remember in relation to those with Alzheimer's disease, but it is one we often forget. Once the group has figured out that the puzzle represents the phrase, "Do not underestimate me," explain its significance as it relates to those with AD.

For most caregivers, it's easy to underestimate the abilities of people with Alzheimer's disease. Yet this is one of the most serious mistakes we can make. Tonight, we're going to talk about why, even in the midst of memory loss, it is so important to recognize the remaining skills and abilities of those with AD. First, though, let's take some time to cover some basic information that will build a foundation for later discussions.

To get us started, we have a short quiz for you to take. It's called a "no-pressure quiz" because it's just that. It won't be graded, and no one will see your answers but you. And those of you with *real* test anxiety can choose to leave your quiz paper blank for now, and just fill in the correct answers as we go!

Once attendees have finished completing their no-pressure quizzes, use the quiz questions to facilitate discussion. The answers to each question are highlighted and in bold (You will notice that each question is followed by related discussion topics in this leader's guide.)

Question #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

What is normal aging?

The term *normal aging* refers to processes that happen to a person purely as a result of the aging process, not due to the presence of disease.

Ask attendees what signs of aging they have noticed in themselves or others. They are likely to mention challenges with vision, hearing, and remembering names (that is, minor memory problems) and more aches and pains in bones and joints. In doing so, they have essentially taught the lesson for you. Highlight discussion points below only as needed.

Normal aging typically involves:

- **Slight (but not severe) memory loss** – You need to concentrate harder on remembering names or new information; you are slower in coming up with answers. Severe memory loss is NOT a part of normal aging.
- **Vision challenges** (Especially less acuity – trouble reading fine print or focusing on small objects – and the need for more light)
- **Hearing loss** (Missing parts of conversation or hearing sounds as muffled)
- **Varying dexterity and mobility issues**, especially if you don't exercise regularly. You may creak as you get out of bed in the morning.

Two points to make:

1. Stress contributes to memory loss and tends to make us accident-prone.
2. The fact that older adults are slower to come up with answers does not mean they are less intelligent. Perhaps an older person's slower processing speed is a matter of him having accumulated so many more experiences than a younger person – similar to the way a computer's hard drive processes slower when it is full of stored information.

Question #2

The two main types of dementia are: reversible dementia and Alzheimer's disease. Is this statement true or false?

- A. True
- B. **False**

What is dementia?

Here are some points to make about 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.
- Some forms of dementia are reversible, which means they may be able to be eliminated with treatment. Common causes of reversible dementias include prolonged dietary deficiencies, adverse reactions to medication, certain infections, operable brain tumors, and depression.
- Irreversible dementias are, by definition, currently incurable, but they can be treated.

The three most common causes of irreversible dementia are:

- **Alzheimer's disease (AD)** - Early onset AD, which occurs between the ages of 30 and 60+, tends to progress quickly and has a strong genetic link. Late onset AD usually occurs after the age of 65 and often progresses more slowly.
- **Vascular dementia** - Formerly called multi-infarct dementia, vascular dementia develops when impaired blood flow deprives the brain of nutrients and oxygen. It may be caused by a single large stroke or multiple small strokes called transient ischemic attacks (TIAs).
- **Dementia with Lewy Bodies (DLB)** - is characterized by strong visual hallucinations, sleep disorders, broad fluctuation in abilities (a person may speak clearly one day but be unable to speak at all the next), and symptoms similar to Parkinson's disease (shakiness, shuffling gait, stiffness, balance problems).
- **Alzheimer's disease is the most common of these**, but many people have a combination.

Question #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**

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 (a person may remain passive throughout the day unless he is assisted to start an activity)

Ask attendees what event caused them to realize their loved one had a problem. As you listen to their responses, they will make the main point of this section: Dementia is *abnormal* aging.

Question #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

How is Alzheimer's disease diagnosed?

There is currently no definitive test to indicate that someone *has* Alzheimer's disease (except autopsying a brain), which means that most testing is done 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

Question #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

What are the benefits of an early diagnosis?

Alzheimer's disease is a frightening diagnosis to face, and yet many find relief in knowing exactly what they are dealing with and in learning about their memory lapses, "It's not my fault." (Ask attendees if that has been their experience.)

Other pluses to being tested early include:

- The chance to be cured if one has a reversible form of dementia
- A chance to benefit from drug treatments that may help to slow the symptoms of the disease.
- Time to plan for the future and 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

How is the progression of Alzheimer's disease measured?

The progression of Alzheimer's disease is usually measured in stages. For many years these were simply called early, middle and late stages, but now the National Alzheimer's Association uses "Reisberg's Global Deterioration Scale," which consists of seven stages. Reisberg's first two stages are considered normal aging. Stages three and four are equivalent to early stage dementia. Stages five and six represent middle stage dementia, and stage seven is equivalent to late stage dementia. (Barry Reisberg, M.D. is a respected neurologist and researcher at New York University.)

The most important thing to remember is that each person with AD remains 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 in stages.

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

The answers begin with the choices in questions 6 and 7.

Question #6

Most individuals with Alzheimer's disease are capable of which of the following from the early stage until late into the disease process?

- A. Being social and polite
- B. Showing pleasure and enjoyment
- C. Appreciating humor
- D. A and B only
- E. **All of the above**

Assisted living communities will often tell you they practice “person-centered care.” This is an idea that was originated by Tom Kitwood, an English psychologist who did not want anyone to underestimate people with AD. Kitwood noted that although those with AD are able to perform fewer tasks over time, they are still full and complete human beings. In fact, he showed ways in which people with AD could do all of the following even late in the disease process:

- 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

Ask attendees for examples of such things they may have noticed in their loved ones.

Question #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

The losses that are noticeable in people with AD in the early stage pertain mostly to tasks they once performed easily but now have difficulty accomplishing. For example, they 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, but they can usually continue to carry on normal conversations
- **Judgment** – which makes them an easy mark for unscrupulous salesmen

Ask attendees for examples of such things they may have noticed in their loved ones.

Most people with AD are aware of their difficulties, but they often try to keep others from noticing by either withdrawing from activities they once enjoyed to prevent making a mistake or covering up their mistakes by making excuses.

Ask attendees if they can give examples of this.

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 the same strengths that had in the early stage. They are still polite and gracious (making good hosts), still interested in being helpful and considerate to others (If they feel *capable* of doing a task, they will do it willingly) and still love to laugh, for example. However, big changes take place between the beginning and end of the middle stage.

Question #8

A person in the middle stage of dementia is not safe living independently. Is this statement true or false?

- A. **True**
- B. False

The most dramatic factor that separates the early stage of Alzheimer's disease from the middle stage is that **a person in the middle stage is not safe living independently**. If she is living with a spouse or adult child, she can get needed assistance from that person, but she cannot live alone. Here are some other 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 and depth perception deteriorates, making the person less sure of her footing. Proprioception (knowing where her body is in space) also deteriorates so that maneuvering through a room can be challenging.

- **Complex tasks** – Many people have problems with apraxia – being able to do ordinary things like getting dressed – and agnosia – understanding the purpose of objects, such as a comb or toothbrush. As the ability to do things related to self-care becomes more challenging, many people have less desire to attempt them. That's why simplifying clothing and breaking down tasks is essential.
- **Memory** – In the early stage of the disease, people may have short-term memory loss, forgetting what they did last week; in the middle stage the loss may extend to the last several years or more – which is why a grandchild remembered as a baby is not recognized now that she is 10.
- **Language** – Let the person with AD set the scope and pace of the conversation. Ask questions that can be answered yes or no or with a simple phrase.
- **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 or fail to throw away spoiled food in the refrigerator.

Ask attendees for specific examples of middle stage behavior they have noticed.

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

There is currently no cure for Alzheimer's disease, so sadly, the late stage ends in death; however caregivers have the power to bring pleasure and positive experiences to those living with AD every day.

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 (although he can be engaged), a tilt to one side when he walks (causing balance problems), an unsteady gait.
- Vocabulary is extremely limited or completely unintelligible.
- Vision and proprioception problems increase, making it increasingly difficult for the person to follow directions like "sit down" or "turn around."
- They become incontinent of bowel and bladder.
- They need assistance with all ADLs (dressing, grooming, bathing) and may need to be hand fed or be given only finger foods.
- They tire easily and may sleep much of the day and night. They may eventually lose the ability to walk and become bedridden.

Question #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

One explanation of how people with AD lose skills is the reverse of Piaget's theory of childhood development: that people lose skills in the reverse order that they acquired them. One of the first things a baby learns to do is smile, and one of the last things a person with AD loses is the ability to smile. That means that people – even in the very end stage of the disease – can enjoy music, gentle hugs and touches and the company of the people who love them, even if the signs that they are aware are extremely subtle, such as the flickering of the eyes or a motion of the hand.

Revisit Handout #1 containing the word puzzle "Do not underestimate me." Summarize this section by explaining that people with AD want us to take their disease seriously, but they don't want it to define them. The fact that can't do *some* things doesn't make them incapable of doing *all* things.

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

The answer begins with the choices in question 10.

Question #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**

Here are a few guidelines regarding ways families can support those with AD throughout the disease process:

- **Do not underestimate them.** What were the personality traits or skills and talents this person was known for before the diagnosis? How can you highlight, nurture and support those?
- On the other hand, people who were once known for a particular skill – knitting fabulous sweaters, for example – may withdraw from that activity when they can no longer follow

a pattern or no longer feel they can do it as well as they once could. Then **look for the parts of the activity that can still be enjoyed** – straight knitting and purling, winding balls of yarn, choosing colors, etc.

- In that same vein, **look for what you can simplify**.
- Most people with AD have **an increasingly low tolerance for crowds, noise and bustle** as their disease progresses, and need increasingly longer periods of time to recover from busy events like a holiday meal. **Be sensitive** to this.
- **Help them to save face** by preventing embarrassing situations. Provide names and introductions and easy conversation starters.
- **Give them opportunities to feel useful**. Many people with AD have a heightened sensitivity to the feelings of others and can be empathetic when, for instance, you are having a bad day. Let them comfort you. Give them tasks. Find opportunities for them to volunteer.
- 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**. Don't make light of their fears or the seriousness of the disease. ("I'm forgetful, too," is NOT helpful to a person with a diagnosis of AD). Do make light of the situations you find yourself in. Seek out people and programs that make you laugh. Humor is our very best coping skill.

This is a point we will make many times. Encourage people to share examples of ways they have used humor. It's a good way to end on a light note. If they don't have a story, be prepared to tell one from your own experience, or use this one told by comedian Steve Allen after he had recovered from a serious illness:

Steve Allen was in the hospital when a team of paramedics poured into his room and he suddenly realized they were there to keep HIM from dying. He was aware that THIS might be his last thought. Then a woman standing in the doorway asked what his condition was so that she could notify his family. The physician shouted back, "He's critical, of course!"

Steve Allen knew his situation was serious, but he couldn't stop his brain from interpreting the statement in an entirely different way: "Sure I'm critical. I'm critical of the food. I'm critical of the nurses, I'm critical of the doctors – and it's going to cost too much, too!"