



the compassion to care, the leadership to conquer

## ***Alzheimer's Disease: In The Beginning An On-line Course***

***“Alzheimer’s Disease: In The Beginning” is the first of a four part series for caregivers.***

*“Alzheimer’s Disease: The Journey Continues”* – discusses topics relevant to the middle stages, such as middle stage behaviors and interventions (including medications), alternative living decisions, stress and the caregiver, respite care, and spirituality.

*“Alzheimer’s Disease: The River’s End”* – discusses topics pertinent to the late stages of Alzheimers, such as late stage behaviors and interventions, end-stage issues and decisions, grief, and planning final arrangements.

*“Alzheimer’s Disease: Life Goes On”* – This seminar discusses topics important to life after Alzheimer’s disease, such as estate settlement, grief, and lifestyle changes and adaptations.

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***Revised 2/08***

## *Introduction*

**Alzheimer's Disease: In The Beginning** is a seminar that will discuss topics important in the early stages of the disease, such as defining Alzheimers, the warning signs, getting a diagnosis, medications, early stage behaviors and interventions, communication, financial and legal issues. It is designed to allow caregivers who might not be able to attend a three-hour seminar in person an opportunity to receive vital information. It is set up to allow the person to read only the parts that are immediately pertinent. It includes a bibliography and additional resources. Many documents are available for reviewing and printing by going to [www.alz.org](http://www.alz.org).

The stories that are included in this seminar are a result of years of experience with Alzheimer's disease. They are not unique. The situations described have occurred many times and do not represent a single incident. Certain facts have been altered to protect the identity of any individual. Some stories have been included with the permission of the family.

**The Alzheimer's Association is partnering with Midland College Health Science Continuing Education to provide professional CEUs such as type II for nursing, social workers, activity directors and other healthcare professionals that accept online training as professional CEU. This seminar has been approved for 3 hours of CEU. In order to receive CEUs, the Midland College Registration form (in order to register, Midland College must have social security number and date of birth), Certificate Request, Evaluation and the post-test must be completed and payment received. The fee is \$25 and may be paid by credit card or check (made out to Alzheimer's Association).**

If you are taking this seminar and need a certificate of completion for personal use, you must take the post-test at the end of the seminar. **There is a \$10.00 fee for a certificate of completion.** The fee may be paid either by credit card (information on credit card payment is available following the post-test) or check (made out to the Alzheimer's Association). Payment must be received before the certificate of completion will be given.

The completed post-test must be submitted to Janet Cross, Program Coordinator, Alzheimer's Association STAR Chapter – Midland Regional Office. The completed forms may be submitted via email to [janet.cross@alz.org](mailto:janet.cross@alz.org), by fax to 432-683-2345, or by mail to:

Janet Cross, Program Coordinator  
Alzheimer's Association STAR Chapter – Midland Regional Office  
4400 N. Big Spring, Suite C-32  
Midland TX 79705

Welcome to **Alzheimer's Disease: In The Beginning.**



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*Alzheimer's Disease: In the Beginning*  
*A Seminar for Caregivers*

OUTLINE

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## *Alzheimer's Disease: In The Beginning* **A Caregiver Seminar**

### COURSE OBJECTIVES

#### **I. Alzheimer's disease – An Overview**

*Participants will be able to –*

- *Identify differences between Alzheimer's disease and normal age-related memory difficulties.*
- *List the two greatest risk factors for Alzheimer's disease.*
- *Identify one other cause of Alzheimer-like symptoms.*

#### **II. 10 Warning Signs**

*Participants will be able to –*

- *List the ten warning signs of Alzheimer's disease.*
- *Identify the first part of the brain impacted by AD and describe the effect.*

#### **III. Getting a Diagnosis**

*Participants will be able to –*

- *Describe the diagnostic process.*
- *Explain the family's role in diagnosis.*

#### **IV. Medications & Alzheimers**

*Participants will be able to –*

- *Explain what a cholinesterase inhibitor is designed to do.*
- *Identify two possible side effects of cholinesterase inhibitors.*

## V. Alzheimers – The Early Stages

### A. Understanding Behavior

*Participants will be able to –*

- *Identify the characteristics of the early stages of Alzheimers.*
- *List three possible triggers for challenging behavior.*

### B. Enhancing Communication

*Participants will be able to –*

- *Describe possible changes in communication resulting from AD.*
- *List three tips for better communication.*

## VI. MedicAlert + Safe Return

*Participants will be able to –*

- *Define the Safe Return program.*

## VII. Financial / Legal Issues

*Participants will be able to –*

- *Identify relevant legal and financial documents.*
- *Describe Medicaid Planning.*

## VIII. Post - Test

## Alzheimer's disease – An Overview

Alzheimers (pronounced AHLZ-hi-merz) is a disease of the brain. The cause is unknown and there is no cure. This disease came from relative obscurity approximately twenty-five years or so ago when it started to affect large numbers of people. Dr. Alois Alzheimer first defined the disease in 1906 after performing an autopsy on a woman in her fifties who displayed symptoms he felt were not a normal part of aging. He observed the presence of amyloid plaque and neurofibrillary tangles that were to become the hallmark features of the disease now known as Alzheimers. It is not a new disease and in fact has probably been around for centuries. There are references to “man’s second childhood” throughout the annals of history. There is a scene from Shakespeare’s King Lear that says:

*“I fear I am not in my perfect mind,  
Methinks I should know you, and know this man;  
Yet I am doubtful; for I am mainly ignorant  
What place this is; and all the skill I have  
Remembers not these garments; or I know not  
Where I did lodge last night...”*

- King Lear, Act IV, Scene 3  
- From “The Forgetting” P. 89

Different terms have been used to describe this condition. It has been referred to as senility, senile dementia, dementia, or just plain “old age”. In all probability, what was being described was Alzheimer’s disease.

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*We were sitting in the den on the couch. She looked at me and said, “Who are you?” I replied, “Jan”. She looked away for a moment and then looked at me again and asked, “Who are you?” “Jan”, I said. Once again she looked away and then turned to me and said quizzically, “Who are you?” I responded once again with “Jan”. We repeated this question and answer probably twenty times in the course of a two or three minute time span. Then I got wise and tried the answer “Jan, Donna’s daughter”, thinking that would clear things up. After all, Donna was one of her cherished granddaughters who had*

*spent every summer of her youth with “Mommy” on the family farm. “Mommy”, as she was known to her family, had come to visit us. The house was filled with family, probably twenty or more of her children, grandchildren, and great-grandchildren. I was thirteen and so excited that she had come to see us but a little confused by this unsettling conversation. When the answer “Donna’s daughter” didn’t seem to mean anything to her, the next time she asked who I was, I responded “Jan, Ival’s granddaughter”. Surely that would satisfy her. Ival, her daughter, was in the kitchen helping fix dinner. How could she not know her own daughter? But her answer was “Who?” I’ll never forget the look on her face. She looked confused and ...lost. I remember thinking, “How sad.”*

*That was my introduction to the world of Alzheimers, though I didn’t know it at the time. It was 1967, long before I heard the term Alzheimers. I thought my great-grandmother was just old. The family said she was senile. It was many years later, as I learned more about the disease, that I knew she had probably had Alzheimers. She journeyed deep into the world of Alzheimers, becoming mean, violent, wandering, and incontinent, recognizing no one. Eventually, her children placed her in a nursing home (something they had said they would never do...but they had never expected anything like Alzheimers) where she died in 1971.*

*Janet Cross, Program Coordinator  
Alzheimer’s Association, STAR Chapter, Midland Regional Officeal Office*

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Only recently has man’s life expectancy reached a point where there are large numbers of people with Alzheimer’s disease. It is now known to be the most common type of dementia. Today there are approximately 5.1 million Americans with Alzheimers and this number is expected to more than triple by mid-century.

Alzheimer’s disease is not a normal part of aging. It is a slowly developing but progressive disease process that destroys the brain. It begins in the hippocampus, the part of the brain that controls short term memory and the ability to learn new things. Everyone forgets, but the difference between normal forgetting and Alzheimer’s disease is the disruption of the ability to function in everyday life. Anyone can lose their keys but most people know how to rectify the situation. The keys have either been placed in a location

that is not where they are normally left or someone has moved them. Regardless of how they came to be lost, a locksmith or second set of keys will resolve the situation. The person with Alzheimers may not just lose the keys but may have the keys and not know what they are for or how to use them. Other examples describing the difference between normal age-related memory difficulties and Alzheimer’s disease include:

<b><i>Activity</i></b>	<b><i>Person with AD</i></b>	<b><i>Normal Age-related memory problems</i></b>
<i>Forgets</i>	<i>whole experiences</i>	<i>parts of experience</i>
<i>Remembers later</i>	<i>rarely</i>	<i>often</i>
<i>Can follow written or spoken directions</i>	<i>gradually unable</i>	<i>usually able</i>
<i>Can use notes</i>	<i>gradually unable</i>	<i>usually able</i>
<i>Can care for self</i>	<i>gradually unable</i>	<i>usually able</i>

*From “An Overview of Alzheimer’s disease and Related Disorders”  
Page 4-5*

The most common risk factor for developing Alzheimers is age. The older a person is, the greater the likelihood of having Alzheimers. For a person over 65, there is a one in ten chance of developing Alzheimers. Over the age of 75, there is a one in five chance. Over the age of 85, the chances are one in two.

Age is not the only risk factor. A family history of Alzheimers, having parents or siblings with the disease, puts a person at higher risk for developing the disease, regardless of their age. There is a type of Alzheimers called early-onset that affects people in their thirties, forties or fifties. While relatively rare, accounting for approximately ten percent of Alzheimers, this type tends to run in families. It is estimated there are approximately half a million Americans with Early-Onset Alzheimer’s. It also tends to progress more rapidly than the more common late onset Alzheimers.

At present, there is no way to slow down the progression of the disease and no way to stop or prevent it. With the coming of age of the baby boomer generation in the next few years, this disease poses a serious threat to the American health care system. Currently, Alzheimer’s disease costs American society approximately \$140 billion a year to provide direct and indirect health care to people with Alzheimers. American businesses are spending \$61 billion a year either on health care or on costs related to

caregivers. This includes employees who are exhausted or distracted because they are caring for someone with Alzheimers (a spouse, parent, sibling, etc.) and therefore not as productive. Maybe the employee is missing work because of the demands of caregiving. Ultimately, the employee may have to retire early in order to care for someone, causing the business to have to replace them with someone less experienced and knowledgeable. Unless significant progress is made and a way to slow down, delay the onset, or prevent this disease is found, Alzheimer's disease will bankrupt Medicare and Medicaid in the next eight to ten years.

***Resources utilized for this section include:***

*An Overview of Alzheimer's disease and Related Dementias*

*fact sheet "What is Alzheimer's disease?"*

*fact sheet "Alzheimer's disease: Statistics"*

***For more information, go to [www.alz.org](http://www.alz.org).***

## 10 Warning Signs

Alzheimers is a slowly developing disease process. By the time the symptoms become apparent to the individual or their family / friends, the disease process has been going on in the brain for approximately twenty years or more. It is a terminal disease, with the individual with Alzheimers living anywhere from two to twenty years following the diagnosis (the average is eight years). Initially, the signs are so innocuous they may not be recognized for months, maybe even years. If the person lives alone, they may be able to conceal their symptoms from their loved ones. If they reside with their spouse, they may be able to cover the signs with the non-effected partner aiding the person with dementia. This aid could come in the form of reminders or notes, possibly even making excuses. The warning signs are confusing, even frightening. Allowing the outside world to notice something is wrong may prompt family or friends to intervene, resulting in the loss of independence.

*“Memory loss that disrupts everyday life is not part of the normal aging process. It is a symptom of dementia, a gradual and progressive decline in memory, thinking, and reasoning skills. The most common cause of dementia is Alzheimer’s disease, a disorder that results in the loss of brain cells.”*

*From “Is It Alzheimers? Ten Warning Signs You Should Know”*

In the beginning, the person may experience problems remembering people’s names. They may struggle to follow conversations, forgetting what was just said or not understanding a word. Words may escape them and they describe the item or function in an attempt to make themselves understood (a pen may become “that thing you write with”). They might become confused about place or time. A simple trip to the store may become a challenge to remember how to get there, what they were going for, and how to get back. They have difficulty remembering what just happened but are clear on events of long ago. As the person realizes something is happening to their ability to recall or understand what is going on around them, they may withdraw from society. This may be in part because they are trying to conceal that they are struggling to function or it may be due to their desire not to take part in something that has become too confusing.

*Have you ever had that experience where someone walks up to you, calls you by name, and starts talking about past events...and you don't have a clue what they are talking about, much less who they are? You hope they don't notice your confusion, don't realize that you haven't recognized them. Maybe they will keep talking long enough to give you a clue as to their identity and where you know them from. In the meantime, you are frustrated and embarrassed with your inability to remember and even a little angry...with yourself and with the person. You try to cover, making innocuous comments in an effort to keep them from realizing that you don't know who they are. This is similar to the experience of a person with Alzheimers, except for them it occurs all too frequently, happening more and more often as the disease progresses. How often would you put yourself in this type of situation?*

Tasks that used to be familiar may become a mystery. Remembering how to do something may prove difficult. Tasks as simple as mowing the lawn or cooking a meal might become a complex maze of steps too difficult to navigate. The person with Alzheimers may stop attempting to do things as the tasks become confusing. The excuse may be “it's too hot to cook” or “the water bill is too high”. Judgment may become impaired and the individual may do things they would not normally do. Behaviors may be displayed that are socially inappropriate such as speaking loudly during church or making derogatory comments about someone. They may give away items of value or large sums of money to people they barely know. Tasks such as balancing the checkbook or managing finances become a challenge. Bills may get paid several times (forgetting that they have already been paid) or not at all. A value such as \$100.00 may become \$10000 as the decimal point loses meaning.

The second part of the brain impacted by Alzheimers is the amygdala. The amygdala is the area of the brain that controls personality and temperament. The individual with Alzheimers may experience rapid mood swings for no apparent reason. They may become depressed or angry when only moments before they were happy. They may become paranoid, making accusations of theft or infidelity when in fact they don't remember where they put something or they don't recognize the people coming in and out of their house.

As the disease progresses, these behaviors will start to occur with greater frequency and for longer durations. As the ability to function in the everyday world diminishes, the individual with Alzheimer's disease may withdraw from society. The world becomes a place of confusion and challenges increasingly more difficult to cope with.

***Resources utilized for this section include:***

*Is It Alzheimers? Ten Warning Signs You Should Know*  
*fact sheet "Alzheimer's disease: The 10 Warning Signs"*

***For more information, go to [www.alz.org](http://www.alz.org).***

*From a family caregiver –*

“For several years, my father exhibited some strange behaviors that I attributed to his individuality and aging. In September and October of 1997, Dad’s behavior became even more bizarre. He began giving away the doors to his house (without having replacement doors), dismantling his wood fence with a claw hammer (this was within 3 months of major bypass surgery), inventing things that had already been invented. He became increasingly delusional. His ability to remember and think clearly was impaired to the point that he had to write every thought down, the problem then became “the pen didn’t write” when in reality, he couldn’t formulate the words and physically write his lists and so his frustration increased. His personality was becoming aggressive, paranoid, and he began hallucinating. In early November 1997, my father was diagnosed with Alzheimer’s disease. I knew something was wrong but I wasn’t familiar with Alzheimers. What should I have been looking for?

## 10 Warning Signs of Alzheimers

**1. Memory loss.** One of the most common early signs of dementia is forgetting recently learned information. While it’s normal to forget appointments, names, or telephone numbers, those with dementia will forget such things more often and not remember them later. **Five to seven years before diagnosis, Dad lost his car and approached all red cars in the airport with no discrimination as to make or model.**

**2. Difficulty performing familiar tasks.** People with dementia often find it hard to complete everyday tasks that are so familiar we usually do not think about how to do them. A person with Alzheimers may not know the steps for preparing a meal, using a household appliance, or participating in a lifelong hobby. **My dad used crude measuring with a fence project after 40 years as a machinist. He used the hand below his chin method even though the ground was uneven.**

**From a family caregiver (continued) –**

**3. Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease often forgets simple words or substitutes unusual words, making his or her speech or writing hard to understand. If a person with Alzheimers is unable to find his or her toothbrush, for example, the individual may ask for "that thing for my mouth." **My father used a description of the use or appearance of an object or person.**

**4. Disorientation to time and place.** It's normal to forget the day of the week or where you're going. But people with Alzheimer's disease can become lost on their own street, forget where they are and how they got there, and not know how to get back home. **Dad pulled up to the wrong house. I could tell he was confused but didn't know why.**

**5. Poor or decreased judgment.** No one has perfect judgment all of the time. Those with Alzheimers may dress without regard to the weather, wearing several shirts or blouses on a warm day or very little clothing in cold weather. Individuals with dementia often show poor judgment about money, giving away large amounts of money to telemarketers or paying for home repairs or products they don't need. **My dad went on a spending spree and put a deposit on a pop-up camper, made arrangements for expensive metal fence, and got angry when questioned.**

**6. Problems with abstract thinking.** Balancing a checkbook may be hard when the task is more complicated than usual. Someone with Alzheimer's disease could forget completely what the numbers are and what needs to be done with them. **I found scratched figuring of math to buy a fence. My dad's addition was wrong and he couldn't multiply.**

**7. Misplacing things.** Anyone can temporarily misplace a wallet or key. A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl. **I found a topless women's calendar in his freezer. Dad's tools were thrown in the entrance of the storage shed. He had always taken meticulous care of his tools.**

**From a family caregiver (continued) –**

**8. Changes in mood or behavior.** Everyone can become sad or moody from time to time. Someone with Alzheimer’s disease can show rapid mood swings—from calm, to tears, to anger—for no apparent reason. **Dad began displaying manic behavior – he didn’t sleep. He was obsessed with his neighbor’s activities.**

**9. Changes in personality.** People’s personalities ordinarily change somewhat with age. But a person with Alzheimer’s disease can change a lot, becoming extremely confused, suspicious, fearful, or dependent on a family member. **My dad became angry when we tried to reason with him about spending money or driving. He was paranoid about his plans for a plastic car and was afraid someone would steal his plans (he got them out of a *Popular Mechanic’s* magazine).**

**10. Loss of initiative.** It’s normal to tire of housework, business activities, or social obligations at times. The person with Alzheimer’s disease may become very passive, sitting in front of the television for hours, sleeping more than usual, or not wanting to do usual activities. **Dad gave up square dancing because the “group was not advanced enough”. He was unable to follow instructions.**

The signs were in front of me. The signs weren’t all together or even all at once until Dad couldn’t hide his confusion any more. Even though I had suspicions I didn’t really heed them until a diagnosis was made and then I didn’t know what to do. I contacted the Alzheimer’s Association in tears and desperation. They gave me literature and someone to talk to. Since then I have read everything I could get my hands on because I have found that knowledge was my key to coping with and understanding this disease.

My father had a massive stroke and passed away on St. Patrick’s Day 2001. I had the honor of being his caregiver. There were times when we laughed together and when we cried together. Dad did unpredictable things that could either embarrass me and/or make me giggle. It was one of the most challenging, frustrating and rewarding experiences of my life so far.”

*Susan M., Family Caregiver*

## Getting a Diagnosis

Once the signs and symptoms become apparent, it is essential to get the person to the doctor for a diagnosis. There can be numerous causes of dementia, many of which are treatable. Thyroid problems, kidney ailments, depression, drug interactions, or infections are just some of the reasons for dementia. These are treatable, maybe even reversible if caught early. If allowed to go undiagnosed and untreated, the dementia may become irreversible. If the diagnosis is Alzheimer's disease (or one of the other age-related dementias), it is still important to get an accurate diagnosis as early as possible. There are medications approved for the treatment of early to moderate Alzheimers that aid the person to function. Knowing what is going on and dealing with the illness allows the person to make decisions that affect the rest of their lives. They can make or participate in decisions involving finances, living situations, or other issues.

When going to the doctor for a diagnosis, there are some things that are essential for the doctor to know. They need to be aware of the behaviors and signs that the person has been displaying. The doctor needs to know when these behaviors / signs first appeared and how often they are occurring. Have there been any changes in the behavior? Write down the information and inform the doctor that there are symptoms he needs to be aware of before he sees the memory impaired person. Do not send a memory impaired person to the doctor alone. They may forget what is happening to them or be afraid to reveal the symptoms. Write down questions for the doctor and take notes of their answers. It can be difficult to recall what the doctor says when trying to inform other family members of the conversation. It might be useful to take in a tape recorder so that there is an accurate and complete record of the doctor's comments.

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*The first call that morning was from a son whose mother had been diagnosed with Alzheimers approximately a year ago. He lived far away and was in town for a visit with his parents. "Do you really think she has Alzheimers? I think she's doing fine. She's still driving (even though the doctor has said she can't). Tell me more about this disease because I don't think she has it."*

*About twenty minutes later, the son called back. He was going to be accompanying his mother to the doctor in a few minutes and wanted to know what questions to ask.*

*A short time later, he called for the third time. He said he didn't realize his mother was as bad as she was. He requested the name and phone number for local certified Alzheimers care facilities.*

*It is not unusual for the person with Alzheimers to be able to function fairly well for brief periods of time. In fact, sometimes they can behave in such a way that it convinces the caregiver that they themselves are the ones with a problem.*

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There is not a single diagnostic test for Alzheimer's disease. It is primarily a diagnosis of exclusion. Using a battery of tests such as a brain scan (either a CT or MRI), blood tests, medical history (including family history), a neurological exam, mental health evaluation, cognitive evaluation, and a physical exam, the physician will start to rule out other causes for the dementia. Alzheimers can be diagnosed with 90 percent accuracy.

Although researchers are making progress in finding answers about Alzheimers, the only definitive way to diagnosis this disease is with a brain autopsy.

***Resources utilized for this section include:***

*Steps to Getting a Diagnosis: Finding Out If It's Alzheimer's disease*

*fact sheet "Alzheimer's disease: Diagnosis"*

*Ethical Considerations: Issues in Diagnostic Disclosure*

***Other useful material includes:***

*Services You May Need*

***For more information, go to [www.alz.org](http://www.alz.org)***

## Medications & Alzheimers

Currently, there are four medications approved by the FDA for the treatment of mild to moderate Alzheimer's disease. One of them, Cognex® (tacrine) was approved in 1993 but is seldom prescribed anymore due to possible liver damage associated with its use. The other three, Aricept® (approved in 1996), Exelon® (approved in 2000), and Razadyne® (approved in 2001), are used to improve cognitive function in people with Alzheimer's disease. This class of drugs, called cholinesterase inhibitors, is designed to slow the breakdown of acetylcholine, a chemical messenger in the brain. By influencing certain chemical activities in the brain, the cholinesterase inhibitor enhances memory and other cognitive functions. Cholinesterase inhibitors are generally well tolerated, with possible side effects of nausea, vomiting, loss of appetite, and increased frequency of bowel movements. Cholinesterase inhibitors are virtually interchangeable when it comes to their impact on the person taking the medication. The specific medication may be determined by the individual's tolerance of the drug. These drugs are not effective for everyone, with approximately 30 – 40% of the people taking them receiving some benefit such as improved memory performance and thinking ability.

The benefit of these medications is measured differently than most medications. These medications will not stop the progression of the disease. There may be a slight improvement in memory and cognition initially. What may be seen is a slower decline in the individual's cognitive functioning. Typically, what the individual experiences is a leveling off of symptoms. This plateau may last one to two years, or even longer. It is uncertain how long the benefit may last but what appears to happen if a person is taken off of the medication is that they experience a dramatic decline in cognitive ability. The ground lost by taking a person off the medication can never be recovered.

There is a new medication that was approved by the FDA in October 2003 for the treatment of moderate to severe Alzheimer's disease. This medication, Namenda®, appears to work by regulating the activity of glutamate, which is one of the brain's chemical messengers. This differs from the cholinesterase inhibitors, which temporarily boost levels of acetylcholine. Glutamate is involved in information processing, storage and retrieval. Namenda® appears to improve a person's ability to perform daily activities. It can be used as a stand alone medication or in conjunction with Aricept®. As with the cholinesterase inhibitors, not everyone will benefit from Namenda®.

There are some general suggestions for taking medications, especially when an individual is memory impaired. The caregiver needs to be involved in medication administration. Develop a routine for giving medication. Do not assume the individual will take medications as prescribed. They may refuse to take the medication or not remember if they have taken it or not. This may lead to overmedicating or under medicating. Medications need to be taken on a regular basis in order to achieve maximum benefit.

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*“She won’t take her medication. I leave it out for her but when I get home she hasn’t taken it. I leave a note to remind her. I don’t understand.” What had been a simple task has become complicated. Understanding the note, or even remembering that there is a note, may be difficult (or impossible). The person with dementia may forget to take the medication or forget that they have already taken the medication.*

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***Resources utilized for this section include:***

*fact sheet “Alzheimer’s disease: Approaches to Care”*

*Medication*

***For more information, go to [www.alz.org](http://www.alz.org).***

## The Early Stages

There are several tools used by doctors to define the stages or progression of Alzheimer's disease. The most common scale (the one utilized by the Alzheimer's Association) identifies three stages: mild, moderate, and severe. The stages of Alzheimer's disease are not easily defined. The distinction between early stage and middle stage is difficult to describe. There is no clear separation between the two. No two people make the journey through the disease process the same way. While there are similarities, every individual's journey is unique.

In the early (mild) stage, people start to have difficulty functioning in every day life. They may have problems at work or participating in lifelong hobbies. A woman who has always been a terrific cook may not cook at all. A man who has always been very active in the community may withdraw from organizations and activities. They may offer excuses such as "I'm too tired", "I don't have time", "It's too hot", or "I'm not hungry." What may be occurring is they are having problems remembering things – dates, times, locations, people. They may be struggling to remember how to do something. A person with Alzheimer's disease starts to struggle with language and multifaceted tasks. A term used to describe the process is retrogenesis, which means "back to birth". If the developmental abilities an infant acquires from birth through the early teenage years is reversed, that approximates the Alzheimers journey. However, this is just a guide. Each individual with the disease travels the Alzheimers journey in their own way, in their own time. Behaviors identified as occurring in the early or mild stage may not occur until later in the disease process (or not at all). Behaviors that typically occur in the middle stage may occur sooner. In the beginning, the behaviors (or Alzheimers moments) may occur occasionally and last a brief period.

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*"I don't think my mom has Alzheimers. The doctor said she does but I don't agree. I was with her yesterday and it was like old times. We laughed and talked and she was fine. I think the doctor's wrong."*

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In the early stages, there are more good moments than Alzheimers moments. The behaviors appear ambiguous, even innocuous. This can make it difficult for family and friends to recognize that something is wrong, much less accept a diagnosis of Alzheimer’s disease. As the disease progresses, the behaviors will occur with greater frequency and last longer.

***Resources utilized for this section include:***

*fact sheet “Alzheimer’s disease: Progression”*

***Other useful material includes:***

*fact sheet “Impact on the Care Partner”*

***For more information, go to [www.alz.org](http://www.alz.org).***

# Retrogenesis\*

## “Back to Birth”

<i>Child Development</i>		<i>Alzheimer's disease</i>	
Age	Acquired Ability	Stage	Lost Ability
1 – 3 months	Can hold up head	Mild	No difficulty at all
2 – 4 months	Can smile		Some memory trouble begins to affect job / home
6 – 10 months	Can sit up without assistance		Much difficulty maintaining job performance
1 year	Can walk without assistance	Moderate	Can no longer hold a job, prepare meals, handle personal finances, etc.
1 year	Can speak one word		Can no longer select proper clothing for occasion or season
15 months	Can speak 5 – 6 words		Can no longer put on clothes properly
2 – 3 years	Can control bowels		Can no longer adjust bath water temperature
3 – 4.5 years	Can control urine		Can no longer use toilet without assistance
4 years	Can use toilet without assistance		Urinary incontinence
4 – 5 years	Can adjust bath water temperature		Fecal incontinence
4 – 5 years	Can put on clothes without assistance		Speech now limited to six or so words per day
5 – 7 years	Can select proper clothing for occasion or season	Severe	Speech now limited to one word per day
8 – 12 years	Can handle simple finances		Can no longer walk without assistance
12+ years	Can hold a job, prepare meals, etc.		Can no longer sit up without assistance
			Can no longer smile
			Can no longer hold up head

\*From “The Forgetting”, pages 122-123

## Understanding Behavior

During the early (mild) stage, the individual with Alzheimer's disease functions well most of the time. Initially the problems will be with remembering what someone just said or what they did a few moments or even days before. Everything may be just fine and then they will have an "Alzheimer's moment".

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*A gentleman came into the office requesting information on Alzheimer's disease. He received several brochures and left the office, only to return a few minutes later. Still holding the brochures in his hand, he requested information on Alzheimer's disease. He had forgotten that he had been in the office a few minutes prior and that he was holding the literature.*

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Most people have experienced an occasion where they are engaged in conversation only to have their mind wander. After all, the human brain can process words at a far greater rate of speed than someone can speak them. When they realize they are expected to respond to something someone has said, rather than admit they weren't paying attention, most people will cover with a noncommittal response so that the other person will keep talking and not realize what has happened. The individual with Alzheimer's may have a similar experience, except they may be struggling to understand what is being said, or follow the entire conversation instead of simply not paying attention. Tasks they used to be able to perform with relative ease may become complicated. As this occurs with greater frequency, they may withdraw from situations that place them in this position.

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*"I stopped driving a couple of months ago. There were a lot of crazy people on the road. They would turn in front of me, go fast by me. It was very confusing. There were way too many cars on the road and I got scared." This person with Alzheimer's found driving frightening and confusing. Fortunately, they made the decision to stop driving on their own and before there were serious ramifications.*

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Remembering that the disease process starts in the hippocampus (the part of the brain that controls short term memory and the ability to learn new things) will help caregivers understand the “Alzheimers world”. The individual with the disease has no control over the disease progression. Their behavior is not personal or intentional. They are not trying to frustrate or irritate their loved ones.

The person with Alzheimers may go to the store to purchase food or household items. They may not only forget the list, but forget that they had a list. They may buy the same item over and over again, every time they go to the store. They may have forgotten that they had even been to the store before.

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*When her father passed away, she went home to help settle his affairs. When she started cleaning out the garage, she found roll after roll of duct tape. Apparently every time her father had gone to the store, he had purchased yet another roll. There were hundreds of rolls of duct tape.*

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The second part of the brain impacted by the disease process is the amygdala. The amygdala controls personality and temperament. The person with Alzheimers may experience mood swings, irritability, anxiety, anger, and depression. This is an extremely trying time for family and friends. Often the changes occur with little warning, no apparent cause, and last an unknown amount of time.

There is awareness on the part of the person with Alzheimers that they are losing function and ability. They recognize they are struggling to understand the world around them. As they lose parts of their life, they may grieve the loss of things they used to be able to do. They may be sad that their life is not as they had planned, that their loved ones will become their caregivers. Language becomes a challenge. They may be frustrated and anxious at their inability to understand and their difficulty in making others understand them. This awareness can lead to depression or anger. Not only is the disease process at work but depression or anger may be a person’s natural reaction to uncertainty and challenges.

Challenging behavior can be caused by certain triggers. If caregivers understand what prompted or exacerbated the behavior, their response will be more effective in resolving the situation. People with Alzheimers function best in calm, stable environments. If there is a lot of activity or chaos around them, they may become agitated or restless. Too many people or too much noise is distressing for them as they try to process the world around them. Being in an unfamiliar environment may be unsettling. They depend on constancy to aid them in functioning.

When people with Alzheimers are challenged to perform complicated tasks, remember or understand what they have been told, or remember who people are or where things are located, they may become frightened by this confusing world around them. Fear inhibits their ability to function. Simplifying the environment and tasks may reduce their anxiety and let them feel in control and able to deal with what otherwise may be a confusing world.

Another possible trigger is physical discomfort. If they are in pain, do not feel well, or are too hot or too cold, they may be restless or upset. If there is something wrong physically the person with Alzheimers may be distressed or agitated. When words fail them they try to find other ways of communicating.

“Shadowing” is a fairly common behavior. The individual with the disease may attach themselves to their caregiver following them everywhere. They are fearful and uncertain when their caregiver is out of sight even for a short period of time. They do not remember that their loved one is coming back and they are afraid of being left behind. The caregiver becomes a source of security and stability. In a frightening and confusing world the caregiver is the anchor and interpreter.

Using medication to control challenging behavior is not the answer. Medication for these behaviors should be a last resort and only short term. A stable and calm environment will provide the best opportunity for a person with Alzheimers to cope with this ever changing world.

***Resources utilized for this section include:***

*Steps to Understanding Challenging Behavior: Responding To Persons With Alzheimer's disease*

*FACTS: About Agitation and Alzheimer's disease*

*FACTS: About depression and Alzheimer's disease*

***Other useful materials include:***

*Steps to Assisting With Personal Care: Overcoming Challenges and Adapting to the Needs of Persons with Alzheimer's disease*

*Steps to Planning Activities: Structuring the Day at Home*

*Steps to Enhancing Your Home: Modifying the Environment*

*Steps to Ensuring Safety: Preventing Wandering and Getting Lost*

*FACTS: About sleep changes in Alzheimer's disease*

***For more information, go to [www.alz.org](http://www.alz.org).***

## Enhancing Communication

During the beginning stage the individual with Alzheimers will experience problems with language. They will have difficulty following a conversation and might struggle to find the right word. They may make up words or use descriptions of an object rather than the name of the item. They may mix parts of several stories into one. Avid readers may stop reading as they find it difficult to follow the story line. This is frustrating for the person with Alzheimers as well as their family and friends.

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*“My wife is losing weight. She says she’s not hungry.” When preparing his own meal her husband would ask her if she wanted to eat. She kept saying no. When the suggestion was made that he prepare her something to eat anyway and put it in front of her he found that she was indeed hungry.*

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There are some simple tips that might help. First, always approach the person with Alzheimers from the front. This helps them realize that someone is talking to them. Approaching from behind or the side may startle them. They may have difficulty determining where the sound is coming from. Remember, the brain interprets everything – auditory and visual. Second, call them by name. John, Sue, Mr. Jones, Mrs. Smith – whatever they are normally called. Do not use terms of endearment such as “honey”, “dear”, or “sweetie”. This does not help them realize that someone is talking to them or remind them of their name. Third, tell them who you are. “Hi, Mrs. Jones, it’s Janet.” Now they don’t have to guess your name. Fourth, identify the purpose of the desired interaction. “Hi, Grandmother, it’s Janet. Let me help you get dressed.” This tells them who they are, the relationship with the person talking to them, and what is about to happen. Above all, stay calm. The goal is to remove challenges and assist them in coping in an otherwise confusing world.

The individual with Alzheimers will slip back and forth between the Alzheimers world and reality. Because their short term memory is the first area impacted by the disease process they revert to memories of many years ago. This explains why they may not recognize friends or family. The aging process has changed most people to the extent that the person with AD (Alzheimer’s disease) does not know who they are. They remember them as much younger, looking very different. For the caregiver the challenge is to

go where the person with AD (Alzheimer's disease) is in their memory. This could be thirty, forty, fifty or more years ago. The key to communicating with them is to not argue. It is their reality. The caregiver must enter their world not insist that they return to the caregiver's reality.

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*Grandmother was falling asleep in her chair. The family kept asking her if she wanted to go to bed. "No", she said. After about an hour of constantly asking if she wanted to go to bed, someone finally rephrased. "Let me help you to bed", they said. "Okay", Grandmother replied. Once in bed, she fell asleep immediately.*

*Janet Cross, Program Coordinator  
Alzheimer's Association – STAR Chapter, Midland*

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***Resources utilized for this section include:***

*Steps to Enhancing Communication: Interacting with Persons with Alzheimer's disease*

***For more information, go to [www.alz.org](http://www.alz.org).***

At some point in the disease process, the person with Alzheimer's disease or related dementia may start to wander. This behavior is extremely stressful for the individual with Alzheimers and their caregiver but is all too common. Approximately 60% of individuals with Alzheimers will wander, and may do it repeatedly. They may get lost in their home, their neighborhood, the store, or somewhere far from home. They may be on foot, in a car, or any means of transportation.

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*Mommy would sit at the front door with her suitcase waiting for someone to come take her home. The neighbors called one day to tell the family that Mommy was walking down the middle of the street with her suitcase. She had never wandered before.*

*Janet Cross, Program Coordinator  
Alzheimer's Association – STAR Chapter, Midland*

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While not every person with Alzheimer's disease will wander, it is important to be prepared and to take steps to help them return safely should they become lost and disoriented. The Alzheimer's Association's **Safe Return Program** is the only nationwide system designed to help identify, locate and return individuals with dementia who wander and become lost.

“Safe Return provides:

- a national, 24-hour, toll free number to contact when someone is lost or found.
- identification products for the memory-impaired, including a bracelet or necklace, clothing labels, and wallet card. These products alert others that the individual is memory-impaired and may need assistance and also list the **Safe Return** 24-hour crisis number.
- registration in a national database including important information that can be accessed quickly when someone wanders and gets lost. This information can be critical in helping law enforcement agencies and others in their search.
- connection to more than 81 community-based Alzheimer's Association chapters across the country that offer assistance and

support. Some chapters have scholarship programs to help pay for the registration fee.

- Safe Return is now partnered with MedicAlert and includes a personal health record.
- 

To register:

Complete a **MedicAlert + Safe Return** registration form. To obtain a copy, contact your local Alzheimer's Association at (800) 272-3900, contact MedicAlert + Safe Return at (888) 572-8566 or download the form from the Association's Web site at [www.alz.org](http://www.alz.org) or [www.medicalert.org/safereturn](http://www.medicalert.org/safereturn). ”

*From Safe Return: For safety and peace of mind – Registration Brochure*

***Resources utilized for this section include:***

*Safe Return: Fact Sheet.*

*Safe Return: Registration Form.*

***For more information, go to [www.alz.org](http://www.alz.org).***

## Financial / Legal Issues

The time to plan for the future is now. One of the greatest gifts a person can give their family is to place their affairs in order and make their wishes known. This can save their loved ones a great deal of grief as well as time and money. Crisis situations are not the time when someone should be making life-altering decisions. Emotions may get in the way of logic and reason. The earlier these issues are dealt with the easier it is on everyone involved.

There are several legal documents that are essential to planning for the future. Durable power of attorney for asset management will allow the designated person to make the necessary financial decisions. It is a good idea to designate several people to have this authority. That way, if the primary person is unavailable, there is an alternate who has the authority to make appropriate decisions.



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*“Without the appropriate legal documents it is extremely difficult to prepare for the future. Without legal authority to make important decisions families are often faced with loss of assets or a prolonged legal battle.”*

*Michael Melson, Registered Financial Consultant  
Michael Melson with Melson and Associates works under the  
direction of attorneys.*

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As the disease progresses, the person with Alzheimers may have difficulty with financial issues. They may pay a bill several times forgetting that they have already paid it. They may not pay bills because they have forgotten how to write the check or address the envelope. They may give away large sums of money indiscriminately.

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*“I didn’t realize there was a problem until the bank called. My spouse had spent all our money even our retirement. We were severely in debt. It took me years to recover.”*

*Family Caregiver*

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At some point the family will have to step in to handle financial and legal affairs. Without the legal authority to do so this may be extremely difficult. It is so much easier if the individual with Alzheimers has named who they want to handle their affairs and the appropriate legal documents are in place. A will insures that financial resources are distributed in accordance with the individual's wishes.

Durable power of attorney for health care allows the designated person to make decisions about medical care for the person who grants the power. This can include who to utilize to provide services, which facility to choose, as well as end of life decisions. By designating someone to have this authority, the person with AD insures that their wishes will be followed. A living will (advance directive) will inform loved ones of how a person with AD wants to be cared for when they are no longer capable of making decisions.

By planning ahead, it is possible to legally protect financial assets and resources. It is important to talk to someone with the knowledge and requirements of the state of residence. Requirements differ from state to state and change annually.

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*The average cost in 2004 in the state of Texas for nursing home care is \$34,896. This figure changes every year.*

*“Planning for the future is essential. If a person has Alzheimers, there is a strong possibility they will end up in a nursing home. There are legal ways to save thousands maybe hundreds of thousands of dollars by preparing for the future. Every state is different and the requirements change yearly. It is important to work with someone familiar with state requirements.”*



*Michael Melson, Registered Financial Consultant  
Michael Melson with Melson and Associates works under the  
direction of attorneys.*

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***Resources utilized for this section include:***

*Steps to Understanding Legal Issues: Planning for the Future*

*Steps to Understanding Financial Issues: Resources for  
Individuals with Alzheimer's disease*

*Steps to Understanding Financial Issues: Resources for  
Caregivers*

***For more information, go to [www.alz.org](http://www.alz.org).***

## Conclusion

Hopefully, the information in this seminar has been useful. This is just the beginning, the first of a four part series. Information on moderate (middle stage) Alzheimers will be provided in the seminar “Alzheimer’s disease: The Journey Continues”. This will be followed by the seminar “Alzheimer’s disease: The River’s End” which will address late stage (severe) or end of life issues. The final seminar will be “Alzheimer’s disease: Life After Alzheimers”. “Alzheimer’s disease: In The Beginning” is not intended to provide all the answers. The cause of this disease remains unknown. There is still no cure.

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*“I’ve decided I’m not having this ... thing.” This is a typical reaction for individuals with Alzheimers or their families. It is easier to ignore the reality and pretend it is not happening. This can lead to procrastination and missing the window of opportunity to take care of legal, financial, and family affairs.*

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The Alzheimer’s Association believes that through education caregivers will be supported in their journey through this process. The Alzheimer’s Association provides information, referral, education, and support. Support groups are an important part of the journey offering insight into the disease and its’ effect on the family and the individual with the disease.

There is hope. The Alzheimer’s Association just launched a new campaign. “Maintain Your Brain” advocates a healthy lifestyle – healthy eating, exercising, and keeping the mind active to promote healthy aging.

The Alzheimer’s Association is the largest private funder of Alzheimer research. The last fifteen years have seen tremendous advances in understanding the mystery of Alzheimer’s disease. *“...today it is not a question of whether the disease can be prevented but rather when the Association’s vision of a world without Alzheimers will be achieved.”\**

*\* from the fact sheet “Maintain Your Brain”*

***Resources utilized for this section include:***

*fact sheet “About the Alzheimer’s Association”*

*fact sheet “Maintain Your Brain”*

*fact sheet “Changing the Way Americans Think About Alzheimer’s disease”*

*fact sheet “Alzheimer’s Association: Our Commitment to Research”*

*fact sheet “Alzheimer’s Association: Chapter Network”*

***For more information, go to [www.alz.org](http://www.alz.org).***

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## **ADDITIONAL RESOURCES**

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**About Aluminum and Alzheimer's disease.** 6/20/02.
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**About Chronic Wasting Disease.** 4/11/03.
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**About CX516 (Ampalex™), a Drug under Investigation for Treating**  
**Alzheimer's disease.** 4/18/03.
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## Short List of Alzheimer Web Sites

### ALZHEIMER'S DISEASE

**Alzheimer's Association** – <http://www.alz.org>

The Alzheimer's Association, a national voluntary health organization, provides information and services to people with Alzheimers, caregivers, researchers, physicians, and health care professionals.

**Alzheimer's disease: Unraveling the Mystery** – <http://www.alzheimers.org/unraveling/index.html>

This on-line booklet from the National Institutes of Health provides basic information about Alzheimer's disease and research and includes numerous graphical representations.

**Alzheimer Forum** – <http://www.alzforum.org>

A compendium for researchers, physicians and the general public, the site includes news, articles, discussion forums, interviews, diagnostic and treatment guide, directory of drugs and clinical trials, and research advances. It also provides access to such unique tools as directories of genetic mutations, antibodies, patents, and conferences.

**ADEAR (Alzheimer's disease Education and Referral Center)** – <http://www.alzheimers.org>

ADEAR maintains information on Alzheimer's disease research, diagnosis, treatment, drugs, and clinical trials, and Federal Government programs and resources.

**Health Information on AD from the National Library of Medicine** -

<http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html>

An all-in-one search site, this page provides links to recent news items, symptoms and diagnosis, research, statistics, clinical trials, coping issues and other resources.

**Alzheimer's disease Brain** - [http://www.pueblo.gsa.gov/cic\\_text/health/alzheim/brain.gif](http://www.pueblo.gsa.gov/cic_text/health/alzheim/brain.gif)

The site illustrates degenerative neurons in the brain and the areas responsible for motor, vision, sensory, speech and memory functions.

**Alzheimer's disease Process in RealMedia** – <http://www.alzheimers.org/rmedia/mediaroom.htm>

In a 2-minute captioned film clip the viewer can learn about neurons, neurotransmitters, tangles and plaques, and the death of nerve cells.

**Normal and Alzheimer Brain Comparison** –

<http://www.macalester.edu/~psych/whathap/UBNRP/alzheimer/symptoms.html>

Viewable are lateral and overhead scans of a normal brain and an Alzheimer brain with the areas of memory, understanding, hearing, speech, temper, personality, and brain atrophy labeled.

### CAREGIVING

**Caregiver's Handbook** - <http://www.adrc.wustl.edu/alzheimer/care.html>

Although this handbook is not specific to Alzheimers, it is easily applicable to AD, provides good coverage on care for the caregiver and is copyright free - making it an excellent training tool.

**Caregiving Tips from the Perspective of the Person with Dementia** -

[http://www.familycaregiversonline.com/fcgo\\_text/dementia\\_perspective.html](http://www.familycaregiversonline.com/fcgo_text/dementia_perspective.html)

An Australian writer who has Alzheimer's disease provides practical advice on how to handle 20 caregiving situations.

**Family Caregiver Alliance** – <http://www.caregiver.org/caregiver/isp/home/jsp>

Family Caregiver Alliance, National Center on Caregiving offers factsheets, monographs, statistical documents, consumer and training publications on a full range of caregiving topics. Most of the resources are free to download. The site includes a page on Alzheimers with a listing of symptoms by stage of the disease. Information is available in Chinese and Spanish.

**Mayo Clinic Alzheimer's disease Center** – <http://www.mayoclinic.com/home?id=3.1.2>

The Mayo Clinic site contains articles on driving, caregiving tips, nutrition, communication, stress management, depression, interactive caregiver stress tools and a free e-mail update service.

**Planning for Long-term Care** – <http://www.alzheimers.org/pubs/longterm.html>

This web site from the National Institute on Aging explores the options for long term care, with articles on planning ahead, making the right choice, and making a smooth transition.

**Predicting Time in the Nursing Home** - <http://cpmcnet.columbia.edu/dept/sergievsky/predictor.html>

Columbia University has developed a tool to help predict how long it might be until a person with Alzheimers requires nursing home care. See the home page for their methodology.

**Rush Manual for Caregivers from Rush Alzheimer's disease Center** –

[http://www.rush.edu/patients/radc/pdfs/Caregivers\\_Manual.pdf](http://www.rush.edu/patients/radc/pdfs/Caregivers_Manual.pdf)

Written for family caregivers the manual contains 30 chapters on stages, treatment, communication, intimacy, coping, spiritual needs, legal matters, traveling, driving, exercise, hygiene, incontinence, and nutrition and more. Viewers can download the manual in PDF for free; click Caregiver's Manual.pdf.

**The Alzheimers Page from Washington University in St. Louis** - <http://www.adrc.wustl.edu/alzheimer>

This site links aging and dementia sites and contains the ALZHEIMER discussion group (an on-line support group for family caregivers and professionals).

## OTHER TOOLS

**Alzheimer Disease International (ADI)** - <http://www.alz.co.uk>

The ADI web site links to fifty-seven Alzheimer's disease associations throughout the world, most in developing countries. It lists information about AD (for the person with AD and the caregiver - in English and in 25+ languages.) It also contains information on the global impact of Alzheimers as well as other activities of ADI.

**ClinicalTrials.gov** - <http://clinicaltrials.gov>

Persons with Alzheimer's disease, family members and members of the public can find current trials and research. The searchable database provides information on the name of the study, the purpose, eligibility, and contact information. Additionally the site indicates whether the study is recruiting and includes citations from published works.

**Manual of Geriatrics** - [http://www.merck.com/pubs/mm\\_geriatrics](http://www.merck.com/pubs/mm_geriatrics)

This Internet version of the manual is intended to help both families and professionals find descriptions and treatment information on conditions prevalent in the elderly. Nineteen sections, averaging ten chapters each cover a wide range of disciplines and geriatric diseases.

Prepared by the Benjamin B. Green-Field National  
Alzheimers Library and Resource Center  
225 North Michigan Avenue, 17<sup>th</sup> Floor  
Chicago, IL 60601-7633  
312-335-9602  
[greenfield@alz.org](mailto:greenfield@alz.org)  
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