Caring for a Loved One with Alzheimer's Disease

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Alzheimer’s Disease /No Boundaries

• Today, 1 in 3 American senior dies with Alzheimer's or another dementia.
• New figures now show that nearly two-thirds of the AD population are women.
• African Americans are 3 X more likely to have AD in later life
• There are research studies that show higher Education offers some protection (however, could just reflect healthier lifestyle)
Alzheimer's Disease Population

- 2015 an estimated 5.3 million Americans were living with AD
- Our nation’s cost is more than $226 billion
- Projected by 2050 these costs could go as high as $1.1 trillion
- Scientific discovery/therapies that yield a modest delay of 5 years in the onset of the disease can change this trajectory
  - The number cut nearly in half by 2050
  - Savings of $447 billion
  - 2015 data Alzheimer's Association
What is Alzheimer’s Disease?

• Alzheimer's is the most common form of dementia
• Alzheimer's is not a normal part of aging
• Alzheimer's worsens over time
• Alzheimer's has no current cure, but treatments for symptoms are available and research continues

• Stages
  – **Earliest Alzheimer's** - changes may begin 20 years or more before diagnosis.
  – **Mild to moderate Alzheimer's stages** - generally last from 2 - 10 years.
  – **Severe Alzheimer's** - may last from 1 - 5 years.
<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Brand Name</th>
<th>Approved For</th>
<th>FDA Approved</th>
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<tbody>
<tr>
<td>1. donepezil</td>
<td>Aricept</td>
<td>All stages</td>
<td>1996</td>
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<td>2. galantamine</td>
<td>Razadyne</td>
<td>Mild to moderate</td>
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<td>3. memantine</td>
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<td>Moderate to severe</td>
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<td>4. rivastigmine</td>
<td>Exelon</td>
<td>All stages</td>
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<td>5. donepezil and memantine</td>
<td>Namzaric</td>
<td>Moderate to severe</td>
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### What is the Difference Between Alzheimer's and Typical Age-Related Changes

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

Stage 1: No Impairment
During this stage, Alzheimer’s disease is not detectable and no memory problems or other symptoms of dementia are evident.

Stage 2: Very Mild Decline
The senior may notice minor memory problems or lose things around the house, although not to the point where the memory loss can easily be distinguished from normal age related memory loss. The person will still do well on memory tests and the disease is unlikely to be detected by physicians or loved ones.
Challenges

- Even during the very early stage of Alzheimer's Disease, people with AD may have difficulty initiating and maintaining a new behavior or routine on their own.

- May not drive independently - making it difficult to get to a gym or health club.

- Caregivers may be in poor health and not able to motivate and help an Alzheimer’s patient maintain a physical activity program.
Stage 3: Mild Decline

Friends and family members may begin to notice memory and cognitive problems. Performance on memory and cognitive tests are affected and physicians will be able to detect impaired cognitive function.

In stage 3 will have difficulty in many areas including:

- finding the right word during conversations
- remembering names of new acquaintances
- planning and organizing
- may also frequently lose personal possessions, including valuables.
Challenges for early stage AD

• May be difficult for early stage patients to keep track of the date and of appointments. AD patients can get lost or disoriented when away from home.

• The ability to read is preserved, but the rapid forgetting that occurs makes the activity generally unsatisfying.

• Patient can carry on a coherent one-to-one conversation, but will get lost in a complex discussion, particularly if several people are involved.
7 Stages of Alzheimer's Disease

Stage 4: Moderate Decline

In stage four of Alzheimer’s disease clear cut symptoms of Alzheimer’s disease are apparent. Patients with stage four Alzheimer’s disease:

- Have difficulty with simple arithmetic
- May forget details about their life histories
- Have poor short term memory (may not recall what they ate for breakfast, for example)
- Inability to manage finance and pay bills
Challenges for Moderate Stage Alzheimer's

• Persons in the moderate stage of Alzheimer's Disease will experience a worsening of the previous symptoms.

• May no longer be able to comprehend or respond appropriately to conversation directed at them.
  – They may no longer consistently identify their spouse or children, though they will recognize them as someone close to and loved by them.

• Confusing spouses with long-deceased parents, or children with siblings is very common

• They may become suspicious, accusing a son or daughter-in-law, or long-trusted household worker of stealing their belongings or their spouse of being unfaithful.
Challenges for Moderate Stage Alzheimer's

- Frustration engendered by their failing abilities may trigger outbreaks of aggressive behavior.

- Wandering and sleep disturbances may occur and ability to dress, bathe, shampoo, and brush teeth independently may be lost.

- May be occasional incontinence, made more difficult to manage by patient resistance to wearing absorbent products.
Stage 5: Moderately Severe Decline
They begin to need help with many day to day activities. May experience:
• Significant confusion
• Inability to recall simple details about themselves such as their own phone number
• Difficulty dressing appropriately
Those in stage five maintain a modicum of functionality.
• They typically can still bathe and toilet independently.
• They also usually still know their family members and some detail about their personal histories, especially their childhood and youth.
7 Stages of Alzheimer's Disease

Stage 6: Severe Decline
Need constant supervision and frequently require professional care.

Symptoms include:
• Confusion or unawareness of environment and surroundings
• Major personality changes and potential behavior problems
• Need for assistance/ activities of daily living such as toileting/ bathing
• Inability to recognize faces except closest friends and relatives
• Inability to remember most details of personal history
• Loss of bowel and bladder control
• Wandering
Stage 7 - Final stage of Alzheimer’s disease

• Because Alzheimer’s disease is a terminal illness, patients in stage seven are nearing death.
• They lose ability to respond to their environment or communicate.
• While they may still be able to utter words and phrases, they have no insight into their condition and need assistance with all activities of daily living.
• In the final stages of the illness, patients may lose their ability to swallow.
Ways to Keep a Loved One Who Wanders Safe

1. Location Tracking Applications
These can be used with cell phones, or in some cases, on dedicated devices. One such app is the Comfort Zone Check In app from the Alzheimer’s Association.

2. GPS Devices.
Many at-home medical alert devices come with options for GPS-locating and monitoring.

3. Bracelet, ID sew-in labels in jackets, sweaters
Ways to Keep a Loved One Who Wanders Safe

4. Modification of the Home Environment
Items can be placed strategically around a living space so that caregivers can be alerted if a person is wandering, such as pressure-sensitive mats in front of a door that chime when someone steps on them.
Some dementia patients benefit from clearly labeled doors that say “DO NOT ENTER,”

5. The Safe Return Program
The Alzheimer’s Association also has a program called Safe Return. It’s a 24/7 emergency response service with a small annual fee.
Difficulties in Communication
The person with Alzheimer’s may have problems with:

• Finding the right word or losing his or her train of thought when speaking
• Understanding what words mean
• Paying attention during long conversations
• Frustration if communication isn’t working
• Blocking out background noises from the radio, TV, or conversations
• Being very sensitive to touch and to the tone and loudness of voices
• Remembering the steps in common activities, such as cooking a meal, paying bills, or getting dressed
Communication
Try Some Tips That May Make Communication Easier

• Make eye contact and call the person by name.
• Be aware of your tone, how loud your voice is, how you look at the person, and your body language.
• Encourage a two-way conversation for as long as possible.
• Use other methods besides speaking, such as gentle touching.
• Try distracting the person if communication creates problems.

To encourage the person to communicate with you:
• Show a warm, loving, matter-of-fact manner.
• Hold the person’s hand while you talk.
Communication
Try Some Tips That May Make Communication Easier

• Be open to the person’s concerns, even if he or she is hard to understand.
• Let him or her make some decisions and stay involved.
• Be patient with angry outbursts. Remember, it’s the illness “talking.”

To speak effectively with a person who has Alzheimer’s:
• Offer simple, step-by-step instructions.
• Repeat instructions and allow more time for a response. Try not to interrupt.
• Don’t talk about the person as if he or she isn’t there.
• Don’t talk to the person using “baby talk” or a “baby voice.”
Communication
Be Direct, Specific, and Positive

• Here are some examples of what you can say:
  “Let’s try this way,” instead of pointing out mistakes.
  “Please do this,” instead of “Don’t do this.”
  “Thanks for helping,” even if the results aren’t perfect.

• Ask questions that require a yes or no answer. For example, you could say, “Are you tired?” instead of “How do you feel?”

• Try not to say, “Don’t you remember?” or “I told you.”

• If you become frustrated, take a timeout for yourself.
Since a person with Alzheimer’s has lost the last 20 to 60 years they are living in another time in their mind.

No matter how hard we try we cannot bring back their short term memory. We can, however, take hold of their long term memory and use it to create moments of joy.

This means we need to live their truth.

Jolene Brackey
Whatever age they are living we need to give them a reason why they don’t have to do what they think they have to do.

You need to find that answer that makes them FEEL like everything is OK for the moment. The answers you find will be different for every person.

**Where are my children?**
Answer: Your kids are in school. Your kids are taking a nap upstairs. They just fell asleep. Your kids are at ________ house.

**I have to go to work.**
Answer: It’s a holiday. It’s Saturday or Sunday. The boss called and said he wouldn’t be in, so you are to take the day off.
Simple Pleasures

Think back when you were a child and all the simple pleasures you found: watching ants build their house, lying under the stars, running out in the rain, licking a lollipop, eating ice cream, walking through tall grass, finding a new flower, searching for beautiful rocks. We all need to relive these simple pleasures again.

A simple pleasure for an older person might be those things, and it might be having their hair combed slowly, getting a back rub, getting lotion rubbed into their hands...

“People will forget what you said, People will forget what you did, But the feeling you leave them with will linger on.”
Focus on Simple Pleasures

Photocopy old pictures which bring fond memories and write under the picture who is in it so ANYONE can give the person their history back
Plant a small garden for our community
Read to anyone here (e.g., poetry, letters, newspaper, Reader’s Digest)
Purchase books on tape and gift them to our community
Bring two rakes and rake leaves with someone here
Find someone to help you fill the bird feeders
Help someone write a letter to a friend far away or family close by
Go for a walk with someone
Bring your children
Invite someone to church
Share your talents (e.g. playing an instrument, reading poetry, arranging flowers)
Pray a familiar prayer with someone
Give a back rub
Rub lotion into their hands
Clean someone’s glasses
Send mail
Look through a jewelry box together
Have a tea party
Share your family pet
Routine & Enhanced Dining

Ritual they had in their youth
Tradition
Look, Feel and Smell Like a Dining Room – no
TV, table cloth
Contrast color dishes
Easy to use utensils
Pictures on the wall
Grandma’s Kitchen
Sit facing each other, you eat as well
Help with clean up
Exercise and Alzheimer’s

- Boosts physical and emotional health
- Reduce the toll of depression
- Preventing falls
  - Greater risk due to impaired mobility / loss of independence
  - Moderate exercise improves strength and coordination
- Improves Sleep
  - Night wandering (caregivers don’t sleep either!)
- Improve Quality of life
  - Help control general health problems
  - Improve strength and flexibility
  - Delay nursing home placement
Put a Little Sunshine in Your Exercise Routine

Individuals with Alzheimer's are particularly deficient in melatonin.

Daylight is known to enhance melatonin levels that decrease markedly with age, in addition to being responsible for resetting the body clock.
Caregiver or Those with Early Memory Problems: 
Be as Healthy as You Possibly Can

You can take steps to keep your brain and body as healthy as possible - include:

- Exercise regularly.
- Eat a healthy diet that is rich in fruits and vegetables.
- Spend time with family and friends.
- Keep your mind active.
- Control type 2 diabetes.
- Keep blood pressure and cholesterol at healthy levels.
- Maintain a healthy weight.
- Stop smoking.
- Get help for depression.
- Avoid drinking a lot of alcohol.
- Get plenty of sleep.
- Talk with your doctor if you or someone close to you sees changes in your memory or thinking.
You Can do It!
A Mediterranean Diet!
Twelve Steps for Caregivers

1. Although I cannot control the disease process, I need to remember I can control many aspects of how it affects my relative.

2. I need to take care of myself so that I can continue doing the things that are most important.

3. I need to simplify my lifestyle so that my time and energy are available for things that are really important at this time.

4. I need to cultivate the gift of allowing others to help me, because caring for my relative is too big a job to be done by one person.
Twelve Steps for Caregivers

5. I need to take one day at a time rather than worry about what may or may not happen in the future.

6. I need to structure my day because a consistent schedule makes life easier for me and my relative.

7. I need to have a sense of humor because laughter helps to put things in a more positive perspective.

8. I need to realize that my relative is not being difficult on purpose rather their behavior and emotions are distorted by the illness.
Twelve Steps for Caregivers

9. I need to focus on and enjoy what my relative can still do rather than constantly lament over what is gone.

10. I need to increasingly depend upon other relationships for love and support.

11. I need to frequently remind myself that I am doing the best that I can at this very moment.

12. I need to draw upon the Higher Power, which I believe is available to me.

Resources

You can find this Pocket Film - and 3 more at AboutAlz.org

Best short film on AD and the brain
NIA Alzheimer’s Disease Education and Referral (ADEAR) Center
1-800-438-4380  http://www.nia.nih.gov/alzheimers

- Focus on latest research-based information on Alz & other dementias
- Referral to government & organization resources, clinical trials
- Bilingual (English/Spanish) Information Specialists
- Free consumer & professional publications

Call Center:
Mon-Fri, 8:30am-5:00 pm Eastern
NIA ADEAR Caregiving Tips & Info

Get tips for caring for a person with Alzheimer’s disease.

https://www.nia.nih.gov/alzheimers/topics/caregiving

- Free publications & e-Books
- Videos & resource lists
- Links to support agencies & organizations
- Featured: Comprehensive caregiving guide

Federal Internet Sites

http://alzheimers.gov

http://Aging.gov