

Coping with Alzheimer's:



Problems with Wandering

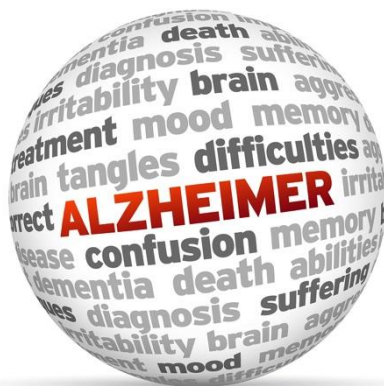
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Introduction

The eBook that you are reading right now is part of a series of articles addressing difficult behaviours in dementia care.

Most of them have been posted already on our [website](#). They include: problems with bathing, problems with dressing, problems with incontinence, but wandering is by far the riskiest, and therefore requires more attention to detail in solving it.

I am, as a matter of courtesy starting this book out with an overview of Alzheimer's disease, because there always seems to be a piece of the puzzle that people are missing.

Feel free to skip right over it if you just want to get to the causes and solutions to Wandering. And please consider signing up for our newsletter at [Caregiver Relief](#).

The information in the following pages is a synthesis and sometimes a direct copy of materials from a variety of sources including Public Domain literature and "understanding difficult behaviours" from the Geriatric Education Center of Michigan.

ALZHEIMER'S DISEASE

Alzheimer's disease (AD) is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks. In most people with AD, symptoms first appear after age 60.

AD is the most common cause of dementia among older people. Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—to such an extent that it interferes with a person's daily life and activities. According to recent estimates, as many as 6 million Americans are living with AD.

Changes in the Brain in AD

Although we still don't know what starts the AD process, we do know that damage to the brain begins as many as 10 to 20 years before any problems are evident. Tangles begin to develop deep in the brain and plaques form in other areas. As more and more plaques and tangles form in particular brain areas, healthy neurons begin to work less efficiently. Then, they lose their ability to function and communicate with each other, and eventually they die.

Very Early Signs and Symptoms

Memory problems are one of the first signs of AD. Some people with memory problems have a condition called *mild cognitive impairment* (MCI). People with this condition have more memory problems than normal for people their age, but their symptoms are not as severe as those with AD. More people with MCI, compared with those without MCI, go on to develop AD.

Mild AD

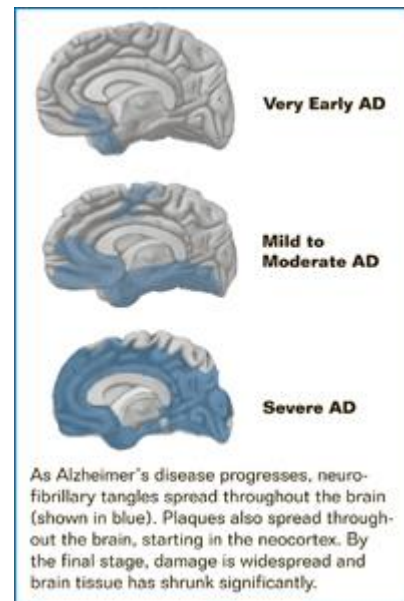
As AD progresses, memory loss continues and changes in other cognitive abilities appear. Problems can include getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, poor judgment, and mood and personality changes. People often are first diagnosed in this stage.

Moderate AD

In this stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought. Memory loss and confusion increase, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out tasks that involve multiple steps (such as getting dressed), or cope with new situations. They may have hallucinations, delusions, and paranoia, and may behave impulsively.

Severe AD

By the final stage, plaques and tangles have spread throughout the brain and brain tissue has shrunk significantly. People with severe AD cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down.



What Causes AD

Scientists don't yet fully understand what causes AD, but it is clear that it develops because of a complex series of events that take place in the brain over a long period of time. It is likely that the causes include genetic, environmental, and lifestyle factors. Because people differ in their genetic make-up and lifestyle, the importance of these factors for preventing or delaying AD differs from person to person.

The Basics of AD

Scientists are conducting studies to learn more about plaques, tangles, and other features of AD. They can now visualize plaques by imaging the brains of living individuals. They are also exploring the very earliest steps in the disease process. Findings from these studies will help them understand the causes of AD.

One of the great mysteries of AD is why it largely strikes older adults. Research on how the brain changes normally with age is shedding light on this question.

For example, scientists are learning how age-related changes in the brain may harm neurons and contribute to AD damage. These age-related changes include inflammation and the production of unstable molecules called free radicals.

Genetics

In a very few families, people develop AD in their 30s, 40s, and 50s. These people have a mutation, or permanent change, in one of three genes that they inherited from a parent. We know that these gene mutations cause AD in these "early-onset" familial cases.

However, most people with AD have "late-onset" AD, which usually develops after age 60. Many studies have linked a gene called APOE to late-onset AD. This gene has several forms. One of them, APOE ϵ 4, increases a person's risk of getting the disease. About 40 percent of all people who develop late-onset AD carry this gene. However, carrying the APOE ϵ 4 form

of the gene does not necessarily mean that a person will develop AD, and people carrying no APOE ϵ 4 forms can also develop AD.

Scientists think that other risk-factor genes exist as well. A possible new one, SORL1, was discovered in 2007. Large-scale genetic research studies are looking to find other genes. For more about this area of research, see the *Alzheimer's Disease Genetics Fact Sheet*, available at www.nia.nih.gov/Alzheimers.



Lifestyle Factors

A nutritious diet, exercise, social engagement, and mentally stimulating pursuits can all help people stay healthy. New research suggests the possibility that these factors also might help to reduce the risk of cognitive decline and AD. Scientists are investigating associations between cognitive decline and heart disease, high blood pressure, diabetes, and obesity. Understanding these relationships and testing them in clinical trials will help us understand whether reducing risk factors for these diseases may help with AD as well.

How AD Is Diagnosed

AD can be definitively diagnosed only after death by linking clinical course with an examination of brain tissue and pathology in an autopsy.

But doctors now have several methods and tools to help them determine fairly accurately whether a person who is having memory problems has “possible AD” (the symptoms may be due to another cause) or “probable AD” (no other cause for the symptoms can be found).

To diagnose AD, doctors:

- Ask questions about the person's overall health, past medical problems, ability to carry out daily activities, and changes in behavior and personality
- Conduct tests of memory, problem solving, attention, counting, and language
- Carry out medical tests, such as tests of blood, urine, or spinal fluid
- Perform brain scans, such as a computerized tomography (CT) scan or a magnetic resonance imaging (MRI) test

These tests may be repeated to give doctors information about how the person's memory is changing over time.

Early diagnosis is beneficial for several reasons. Having an early diagnosis and starting treatment in the early stages of the disease can help preserve function for months to years, even though the underlying AD process cannot be changed. Having an early diagnosis also helps families plan for the future, make living arrangements, take care of financial and legal matters, and develop support networks.

In addition, an early diagnosis can provide greater opportunities for people to get involved in clinical trials. In a clinical trial, scientists test drugs or treatments to see which are most effective and for whom they work best.



How AD Is Treated

AD is a complex disease, and no single “magic bullet” is likely to prevent or cure it. That’s why current treatments focus on several different aspects, including helping people maintain mental function; managing behavioral symptoms; and slowing, delaying, or preventing AD.

Helping People with AD Maintain Mental Function

The U.S. Food and Drug Administration to treat AD approved four medications. Donepezil (Aricept®), rivastigmine (Exelon®), and galantamine (Razadyne®) are used to treat mild to moderate AD (donepezil can be used for severe AD as well).

Memantine (Namenda®) is used to treat moderate to severe AD. These drugs work by regulating neurotransmitters (the chemicals that transmit messages between neurons). They may help maintain thinking, memory, and speaking skills, and help with certain behavioral problems.

However, these drugs don’t change the underlying disease process and may help only for a few months to a few years.

Managing Behavioral Symptoms

Common behavioral symptoms of AD include sleeplessness, agitation, wandering, anxiety, anger, and depression. Scientists are learning why these symptoms occur and are studying new treatments—drug and non-drug—to manage them.

We have created the book, *Dementia Behaviors*, to share with our readers how to use a behavioral approach, before using medications, then dealing with challenging or negative behaviors of dementia.

Treating behavioral symptoms often makes people with AD more comfortable and makes their care easier for caregivers.

Slowing, Delaying, or Preventing AD

AD research has developed to a point where scientists can look beyond treating symptoms to think about addressing the underlying disease process. In ongoing AD clinical trials, scientists are looking at many possible interventions, such as cardiovascular treatments, antioxidants, immunization therapy, cognitive training, and physical activity.

Supporting Families and Caregivers



Caring for a person with AD can have high physical, emotional, and financial costs. The demands of day-to-day care, changing family roles, and difficult decisions about placement in a care facility can be hard to handle.

Researchers are learning a lot about AD caregiving, and studies are helping experts develop new ways to support caregivers.

Becoming well informed about AD is one important long-term strategy. Programs that teach families about the various stages of AD and about flexible and practical strategies for dealing with difficult caregiving situations provide vital help to those who care for people with AD.

Developing good coping skills and a strong support network of family and friends also are important ways that caregivers can help themselves handle the stresses of caring for a loved one with AD.

For example, staying physically active provides physical and emotional benefits.

Some AD caregivers have found that participating in an AD support group is a critical lifeline.

These support groups allow caregivers to find respite, express concerns, share experiences, get tips, and receive emotional comfort. Support networks, such as the group we run on Facebook (**Senior Caregivers**) can be especially valuable when caregivers face the difficult decision of whether and when to place a loved one in a nursing home.

Advancing Our Understanding

Thirty years ago, we knew very little about AD. Since then, scientists have made many important advances. Research supported by NIA and other organizations has expanded knowledge of brain function in healthy older people, identified ways we might lessen normal age-related declines in mental function, and deepened our understanding of AD.

Many scientific and clinical fields are now working together to untangle the genetic, biological, and environmental factors that, over many years, ultimately result in AD. This effort is bringing us closer to the day when we will be able to manage successfully or even prevent this devastating disease.

Understanding Difficult Behaviors

There are many challenges and difficulties associated with Alzheimer's disease, and these challenges can vary between clients. There are several factors that can influence the type of behavior and the strength of the behavior.

Difficult behaviors can appear suddenly or slowly grow from a minor annoyance to a major and dangerous behavior, and they can disappear just as suddenly as they appeared.

It depends of the person's environment, their personal history but also upon which part of the brain is affected or what stage of illness they are in.

The following is a short list of most common challenging behaviors:

- ❖ **Anger and Agitation**
- ❖ **Incontinence**
- ❖ **Repetitive Actions or Questions**
- ❖ **Paranoia and Hallucinations**
- ❖ **Problems with Bathing**
- ❖ **Problems with Dressing**
- ❖ **Problems with Eating**
- ❖ **Problems with Sleeping**
- ❖ **Screaming**
- ❖ **Wandering**

Problems with Wandering

Wandering is an unusual symptom of Alzheimer's disease, most typically it manifests in the late afternoon/early evening as an overwhelming desire in the Alzheimer's sufferer's mind to be somewhere else.

They are very difficult to dissuade and have been known to go to great lengths to 'escape'. When asked, they will tell you that they need to 'go home'.

But having seen hundreds of cases of this, I've concluded that 'home' is not so much a location, as it is a safe place or a safe time in the person's life, where they felt normal and/or safe.

And it goes without saying, that trying to reason with the person that they already are home is a mistake! In most cases it will only escalate the sufferer's desire to leave and will lead to agitation and aggression.

Because this condition usually manifests at the end of the day, around dusk, it is often referred to as "Sundowning".

Researchers believe that this condition is triggered by the circadian rhythm. (The circadian rhythm is a complex 24 hour cycle that exists in every human being, and controls our sleep/wake rhythms, fluctuations in our body temperature, and the natural release and reabsorption of many neurochemicals and hormones in our bodies).

Needless to say, wandering is a big problem for caregivers, but it is not impossible to control, provided the caregiver invest the time and effort to solve and address this problem. That said; let's review some practical suggestions for understanding problem behaviors.



PHYSIOLOGICAL OR MEDICAL CAUSES:

- ✓ Direct result of physical changes in the brain.
- ✓ Inability to identify or express hunger.
- ✓ Reaction to sedatives, tranquilizers, or the interaction of medications.
- ✓ Physical discomfort due to pain, infection, constipation, bruises.
- ✓ Seizures resulting in aimless confused wandering.
- ✓ Need to use bathroom.
- ✓ Desire to exercise.
- ✓ Dehydration contributing to confusion, wandering.
- ✓ Stress.

ENVIRONMENTAL CAUSES:

- ✓ Temperature uncomfortable – too hot or cold.
- ✓ Can't make sense of environment.
- ✓ Sensory overload – too many people or activities, excessive noise.
- ✓ Sensory deprivation – too quiet, boredom.

- ✓ Poor lighting, resulting in shadows which are misinterpreted or frightening. Sometimes people make be looking for light because they are frightened.
- ✓ Feels closed in, trapped.
- ✓ Friend or family member out of sight.
- ✓ Desire to leave triggered by seeing outdoor clothing such as coat, hats, boots, etc.
- ✓ Acting out once regular routine, such as leaving for workplace.
- ✓ Lost. Sometimes people with dementia suddenly begin losing their way to familiar places and become lost.
- ✓ Inability to recognize new unfamiliar surroundings, e.g., person recently begun attending day care program.
- ✓ Feels tension in environment.



OTHER CAUSES:

- ✓ Task too difficult.
- ✓ Perceives activity as too childlike.
- ✓ Feels useless, helpless while watching others do task.
- ✓ Inability to follow through on task.
- ✓ Bored with activity or lack of activity.
- ✓ Clothing too tight or uncomfortable.
- ✓ Caregiver's anger, tension, impatience sensed by person.
- ✓ Touching by caregiver frightening or misinterpreted.
- ✓ Caregiver speaking too quickly.
- ✓ Directions from caregiver not understood, not simply stated.
- ✓ Searching from home or people from the past.

NIGHTTIME WANDERING:

- ✓ Inability to separate dreams from reality.
- ✓ Inactivity; too much sleep during daytime.
- ✓ Adverse reactions to tranquilizers.
- ✓ Inability to differentiate day and night.
- ✓ Disorientation to time. When person wakes up he/she thinks it is time to get up.

COPING STRATEGIES:

- ✓ Have a thorough medical evaluation, particularly if wandering begins suddenly. (Very often it will be a urinary tract infection)
- ✓ Consider possible physical causes such as illness, fever, hunger, pain, swelling, etc.
- ✓ Allow person to wander if environment is safe and secure.
- ✓ Place familiar objects, furniture, and pictures in surroundings.
- ✓ Help direct person with clearly labeled rooms. For example door decorations or name plaques may be useful for finding bedroom; a picture of a toilet or a brightly colored door may help person locate bathroom.
- ✓ Decrease noise levels and number of people interacting with wanderer at one time.
- ✓ Go for a walk around neighborhood, in a mall, around home. Walking or other exercise often reduces agitation that leads to wandering, and also helps person to sleep better.



- ✓ Remove items that may trigger desire to go out: shoes, coat purse, coat rack, etc.

- ✓ Take a drive in the car. Make sure person with dementia is safely buckled in and doors are locked. Never leave a person with dementia unattended in a car. The person may become frightened about being alone, could wander away, release emergency brake or fiddle with gearshifts.
- ✓ Distract with conversation, food, drink or activity.
- ✓ Try to involve person in household activities, such as folding laundry, washing dishes, which will help him/her feel useful.
- ✓ Limit activities to 20-30 minutes or less, depending on level of impairment.
- ✓ Consider past skills and interests when presenting activities. Is it possible to adapt activity to encourage participation? Is it possible for the wanderer to do one type of activity?
- ✓ Make sure the person isn't wandering because he/she needs to use the bathroom. Look for signals such as fidgeting with clothes. At night be sure the bathroom or a commode is easily accessible.
- ✓ Improve lighting throughout environment, especially, at night. Older people need about three times as much light to see properly as younger people.
- ✓ Try placing a large, digital clock by the bed to orient person to time.



Try these communication techniques with wanders:

- ✓ Reassure person frequently about where he/she is and why.
- ✓ Speak in calm, normal tone of voice.
- ✓ Try written reassurances for mildly impaired person, such as “Liz will be here at 3:00 o’clock to pick you up.”
- ✓ Try not to confront or argue with the person.
- ✓ Limit number of people to redirect wanderer. If more than one person is needed for safety, second person can remain out of sight, or in a background behind other caregivers.
- ✓ Increase the wander's trust by humoring and cajoling.
- ✓ Allow the person to verbalize feelings without arguing.
- ✓ Alleviate fears – “Your family knows where you are.”
- ✓ Approach wander in a casual non-threatening manner. It is best to approach wanderer from the front slowly and calmly.
- ✓ Fall into step beside person and walk a short distance with the person before gently guiding him/her back to activity, event or location.
- ✓ Give wanderer verbal identification of person, place and time. Large numeral clocks may help orient to time.

KEEP THE WANDER SAFE

- ✓ Place night lights throughout the house.
- ✓ Try locks on doors that are out of sight or reach. Install slide bolts on either top or bottom of outside door.
- ✓ Use dead bolt locks. Models are available that require a key for exit or entrance. It is important to think about exiting in an emergency if key locks are being considered.
- ✓ Try childproof doorknob covers that prevent potential wanderer from turning doorknob. Covers are available at toy stores or medical supply stores. May be inadvisable for caregiver who has arthritic hands.
- ✓ Place warning bells above door. Bells that jingle when door is opened will signal caregiver.
- ✓ Try monitoring devices, available in a wide price range, which alert caregivers that exit door has been opened.
- ✓ Order a “toddler monitor,” available through children’s stores and catalogs. A small device attached to a person’s clothing will set off a beeper when person goes outside of a 25-50 foot range.

- ✓ Make house accident proof. Keep medications, toxic substances such as cleaning supplies, sharp objects, alcohol, and matches locked in cupboards or closets. Put locks on outside gates. Fenced in back yards allow people to wander safely.
- ✓ Use a safety gate across doors and at top or bottom of stairs. This may help keep the wanderer in a limited area where he/she can explore safely.
- ✓ Try a yellow strip of plastic (symbolizing caution) that can be Velcroed across doors to prevent wanders from entering.
- ✓ Have a plan of action in place, in case someone wanders away from home.
- ✓ Camouflage doors by painting exit doors same colors as walls.
- ✓ Cover doors with curtains or movable screens.
- ✓ A large “NO” sign on doors may discourage wanderer from entering, exiting.
- ✓ Place a full length mirror on exit doors. Some people will turn around when they see the image, not recognizing themselves.
- ✓ Distracting with food, drink or activity may be helpful.



- ✓ Consider using a beanbag chair for sitting and resting. This may be helpful because they are comfortable yet difficult to get out of. Person may need assistance in sitting down and getting out of chair.
- ✓ Provide the wanderer with some type of I.D.: Medic-Alert bracelet (available at many pharmacies), I.D. labels sewn in clothes, emergency cards in wallet, purse or pocket. I.D. should have person’s name, address and phone number and the statement “memory impaired person.”

- ✓ Have a current picture of person available, in case he/she becomes lost. A videotape of person may also be helpful. This can be helpful when a Silver Alert is called.
- ✓ Alert neighbors and police that a memory impaired person lives at residence. Keep a list of important phone numbers, e.g., neighbors, police, physician and family members.
- ✓ Notify police about circumstances in caring for someone with dementia. They might want to keep a picture of person in file and perhaps fingerprints. These may be helpful if the person wanders away.
- ✓ Use brightly colored outdoor clothing such as jacket, coat, and pants. Reflectors sewn onto sleeves or pant legs may be helpful to police involved in searching for the persons.
- ✓ This may sound weird if you are a city person. But in rural settings have an unwashed piece of clothing available for tracking dogs. If person has been missing a long time, this clothing may be helpful to police involved in the search.



KEEPING THE WANDERER COMFORTABLE AND HEALTHY

- ✓ Weigh weekly to make sure the person is not losing too much weight. Loss of five pounds in six weeks, for example, is of concern.
- ✓ Provide comfortable clothing such as jogging suits and tennis shoes.
- ✓ If the person wanders a great deal, try to get him/her to rest for a half hour every few hours, with feet raised to prevent swelling.

Reduce amount of noise, and confusion in the environment. Reinforce where bathrooms and other public areas are by having rooms clearly labeled, painted bright colors, or marked with lights or awning.

OTHER CONSIDERATIONS

- A written diary or log may be helpful to understand what leads to wandering. Write down your observations about wandering for several days. Is the person trying to find a room? What was going on before wandering started? What time of day is it? Consider how medications, mealtime, weather, bath time, other people relate to wandering.
- Wandering may be due to the person searching for a part of life lost to the disease or for a person, place or object from the past. Reminiscing about things from the past may be comforting. Photo albums, travel books, etc., may be helpful ways to reminisce.
- For some people with dementia, wandering is a coping mechanism to relieve stress and tension. Trying to stop the wandering may increase agitation and cause anger and frustration.
- Anticipating an event such as a visit to or from relatives may contribute to wandering. Consider if person should be advised of plans ahead of time and if so, what amount of time is necessary without causing anxiety or restlessness.
- Wandering may occur when a change of location is anticipated. In event of relocation, slowly introduce person to idea. Visit new location several times prior to move to help orient person to new surroundings. Involve person in actual move, if possible.
- When in new environment such as day care center, hospital or long term care setting, stay with person to reassure him/her about new surroundings.
- Medications may be helpful in controlling agitation that leads to wandering. Again, this should be A LAST RESORT as these

medications do have side effects. Also, it is important to know that for some people these medications may increase restlessness.

- A person who wanders at the same time every day may be returning to a former schedule or routine. For example, a person may be trying to get back to work after lunch. Think of ways to accommodate this, such as going for a walk or drive, or distractions. (A good example, Ronald Reagan, as his condition deteriorated, they had an office and everyday he would get dressed up and take to his "office").



Good Luck. Remember: Observe, Predict, Anticipate



More Resources...

There are numerous sources for information about Alzheimer's Disease, Caregiving, and even Managing Difficult Behaviours.

Please feel free to sign up for our free newsletter

<http://www.caregiverrelief.com/>

Also look for more great insider tips and tricks check:

Disclosure

*** I am eternally surprised at how many caregivers using convoluted thinking refuse to accept free help. I hope you are not one of them. And if you are and subscribe to the notion that there is nothing free in life, let me lay all my cards on the table: Yes, there will be things that I am going to charge for, but there will many many more things that I am giving away. Much of it is intangible: information, insider tips, product reviews, and little known government programs. But I want to leave a legacy of helping people, and there is nothing I know better than - helping caregivers.**

I believe in reciprocity - that if one person does something nice or gives away something for free, that they are then inclined to be trusted a little better, and perhaps the receiver of those gifts will be inclined to do business with that person.

So I welcome you all, look around our site, take all the free stuff you need without any strings attached, and if you see something that has a fee or cost, feel free to move on and ignore it.

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