

# GUIDE TO ALZHEIMER'S & DEMENTIA BEHAVIORS

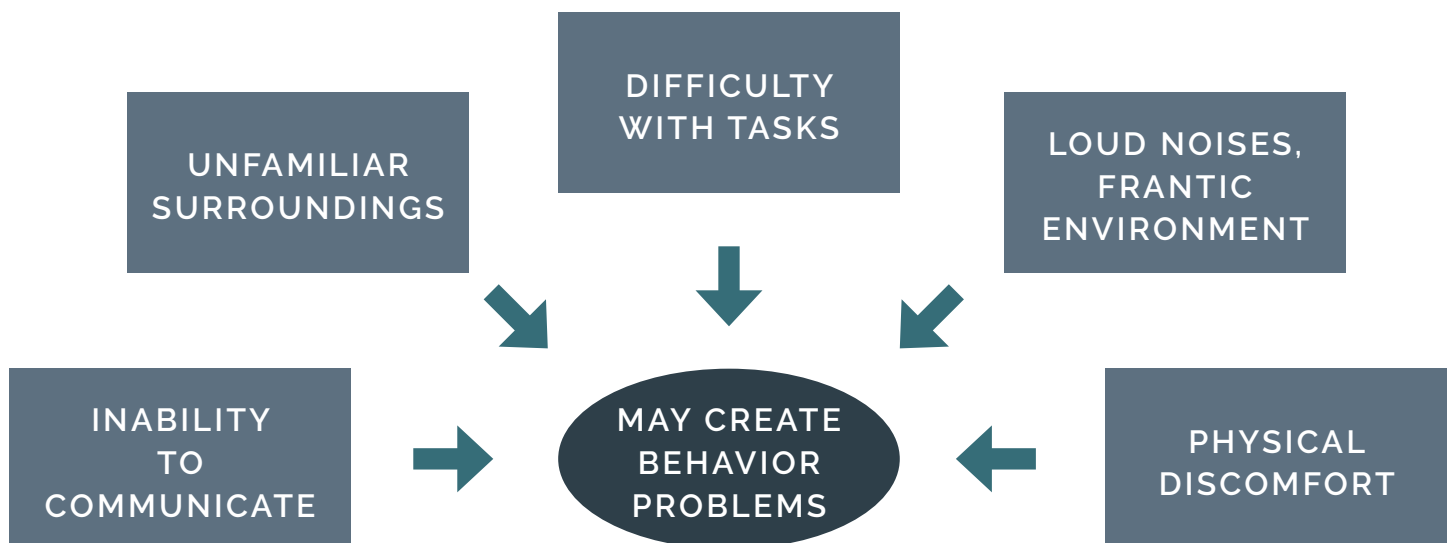
## GUIDE TO UNDERSTANDING AND MANAGING ALZHEIMER'S & DEMENTIA BEHAVIORS

Caring for a loved one with Alzheimer's or other dementias brings fresh challenges. As the disease progresses, your loved one seems to become a different person. They lash out or accuse you of something inappropriate.

The behaviors associated with Alzheimer's disease or other dementias—memory loss, paranoia, aggression, wandering, etc.—can be distressing and make your role as a caregiver more difficult.

It's important to remember that it's not you, it's the Alzheimer's disease or other dementia causing these behaviors. Your loved one's issues often stem from one of these common causes.

### 5 COMMON CAUSES OF BEHAVIORS<sup>1</sup>



SOURCE: HelpGuide.org

## HOW TO USE THIS GUIDE UNDERSTAND THE BEHAVIOR

In this guide, we'll help you better understand your loved one's behaviors. You may experience some or all of them, and they may be present or worsen at different stages of the disease. By understanding the behavior, you can begin to pinpoint a cause and work to reduce or eliminate the triggering event and ease your loved one's stress.

1. HelpGuide.org, <https://www.helpguide.org/articles/alzheimers-dementia-aging/alzheimers-behavior-management.htm>, retrieved 09/16/22.

## IDENTIFY THE CAUSE

As you try to identify the cause, ask yourself the questions below.<sup>2</sup> Those with Alzheimer's disease or other dementias respond less to what you say than how you say it. Use your facial expression, tone of voice, and body language to help project calm and reassurance.

Above all, do your best to maintain your sense of humor rather than take things personally.

- What is your loved one's body language telling you? Think about what they might be feeling or trying to express.
- What happened just before the behavior started...was there a triggering event?
- Are your loved one's physical needs being met...or are they hungry, thirsty, or in pain?
- Does making changes in the environment—for example, dimming the lights or turning on relaxing music—help comfort your loved one?
- How did you react...and did it make the behavior better or worse?

## MANAGE THE BEHAVIOR

Finally, we'll provide some tips for dealing with the behavior. With some simple changes, you can improve your loved one's well-being—and yours!

## IMPORTANT...CHECK WITH YOUR DOCTOR!

Throughout this guide, we'll be addressing behaviors that may be indicative of Alzheimer's disease or other dementias—or another physical or emotional issue entirely. That's why it's critically important to have your loved one evaluated by a healthcare professional for each new behavior as symptoms can often overlap. This is especially true if new symptoms appear suddenly. Your doctor is the best person to diagnose any new issue, provide advice, and prescribe medication, as needed. With proper intervention and treatment, symptoms can often be reduced or eliminated.

## BEHAVIOR: COGNITIVE DECLINE<sup>3</sup>

### UNDERSTAND THE BEHAVIOR

Memory loss and confusion is one of the first signs of Alzheimer's disease or other dementias. In the early stages, when memory loss is relatively mild, your loved one may experience difficulty recalling recent events, making complex decisions, or processing what you've said.

In later stages, memory loss becomes far more severe. Your loved one increasingly fails to recognize you, family members, or friends or to remember names. He or she will forget the relationships between people or become confused about once-familiar locations, such as their home or the passage of time. He or she may even forget the purpose of everyday items, such as a pen or a fork.

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2. HelpGuide.org, <https://www.helpguide.org/articles/alzheimers-dementia-aging/alzheimers-behavior-management.htm>, retrieved 09/16/22.

3. Alzheimer's Association, alz.org, <https://www.alz.org/help-support/caregiving/stages-behaviors/memory-loss-confusion>, retrieved 09/16/2022.

## IDENTIFY THE CAUSE

Memory loss and confusion results from progressive damage to brain cells caused by Alzheimer's disease, but sometimes a change in routine, new living arrangements, or some infections can worsen symptoms.

## MANAGE THE BEHAVIOR

- Stay calm and try not to show your hurt feelings.
- Provide brief, but simple explanations, not long or complicated ones.
- Use photos and other items to provoke memories of people and places.
- Go with your loved one to the period of time she's in and ask about her memories.
- Suggest an explanation rather than make a correction (e.g., "I think this is a spoon").
- Show understanding and try not to take anything personally.

## DEPRESSION<sup>4</sup>

### UNDERSTAND THE BEHAVIOR

Experts suggest that 40-50% of people with Alzheimer's disease experience depression—particularly in the early and middle stages of the disease—compared to 7% of the general population.<sup>5</sup>

Depression can be difficult to diagnose because: (1) symptoms—apathy, loss of interest in enjoyable activities, social withdrawal, isolation, trouble concentrating, and impaired thinking—often overlap with Alzheimer's disease and other dementias and (2) your loved one's cognitive decline often makes it difficult for him or her to fully express their sadness, hopelessness, guilt, and other feelings.

Plus, depression in people with Alzheimer's disease and other dementias may also be less severe and more short-lived, have intermittent symptoms, and have a decreased risk of suicide.

## IDENTIFY THE CAUSE

The high incidence of depression in those with Alzheimer's disease is due not only to changes in the brain from the disease itself, but also to the shock of the diagnosis—especially in the early stages.

## MANAGE THE BEHAVIOR

Treating depression in those with Alzheimer's disease includes therapeutics, counseling, and a gradual return to activities and people that bring your loved one joy. Work with a physician to develop a plan that includes:

- Participating in support groups and/or counseling, particularly if your loved one wants to take an active role in their well-being.

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4. Alzheimer's Association, alz.org, <https://www.alz.org/help-support/caregiving/stages-behaviors/depression>, retrieved, 09/16/2022.

5. "Beyond Memory Loss: How to Handle the Other Symptoms of Alzheimer's," HopkinsMedicine.org.

- Setting a predictable daily routine that considers your loved one's most productive time of the day to perform more difficult tasks, such as bathing.
- Increasing the frequency of activities, people, or places that your loved one enjoys.
- Encouraging regular exercise, especially in the morning.
- Validating your loved one's feelings and expressing hope that they'll feel better soon.
- Celebrating small successes and occasions.
- Finding ways for your loved one to contribute to family life and recognizing him or her for doing so.
- Assuring your loved one that he or she is loved, respected, and appreciated and has an important role in the family.
- Preparing your loved one's favorite foods or engaging them in relaxing or inspirational activities.
- Reassuring your loved one that you will not abandon them.

## EMOTIONAL DISTRESS: ANXIETY & AGITATION<sup>6</sup>

### UNDERSTAND THE BEHAVIOR

Your loved one may gradually lose his or her ability to receive and negotiate new information and situations and feel anxious or agitated as a result. He or she may become restless, feel a need to pace, or become upset in certain places or when focused on specific details.

### IDENTIFY THE CAUSE

Anxiety and agitation may be caused by a number of health conditions, side effects of or interactions between medications, or situations that can worsen your loved one's ability to think, including:

- Moving to a new residence or nursing home
- Environmental changes, such as travel, hospitalization, or the presence of houseguests
- Changes in caregiver arrangements
- Misperceived threats
- Fear and fatigue from trying to make sense of a confusing world

### MANAGE THE BEHAVIOR

- Remove stressors and other stimuli and create a calm environment.
- Avoid environmental triggers, such as noise, glare, or background distractions.
- Ensure your loved one's comfort by monitoring the thermostat and checking for pain, hunger, thirst, fatigue, infection, irritation, and bladder/bowel issues.
- Simplify tasks and routines so they're not overwhelming.

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<sup>5</sup> Alzheimer's Association, alz.org, <https://www.alz.org/help-support/caregiving/stages-behaviors/anxiety-agitation>, retrieved 09/16/2022.

- Find out what triggered your loved one's frustration.
- Involve your loved one in activities to distract from the anxiety-producing trigger.
- Reassure your loved one that you are there and that they're safe.
- Stay calm and do not raise your voice, show alarm or offense, or become combative.

## EMOTIONAL DISTRESS: AGGRESSION & ANGER<sup>7</sup>

### UNDERSTAND THE BEHAVIOR

Aggressive behaviors may be verbal or physical. They can occur suddenly, with no apparent reason, or result from a frustrating situation. While aggression can be hard to cope with, understanding that your loved one doesn't intend to behave this way can help.

### IDENTIFY THE CAUSE

Aggression can be caused by many factors, including:

- **PHYSICAL DISCOMFORT** — Pain associated with urinary tract or other infections can trigger aggressive behavior—and because of his or her cognitive decline, your loved one may be unable to tell you exactly what they're feeling. Hunger, thirst, or sleeplessness—as well as the side effects of and interactions between medications—can also cause your loved one to act out in anger.
- **ENVIRONMENTAL FACTORS** — New or unfamiliar people and environments, loud noises, large crowds, feeling lost, and other factors in the environment can over-stimulate your loved one and cause them to be aggressive.
- **OVERWHELMING COMMUNICATION** — Your loved one may be overcome by complex or confusing instructions, too many questions or demands, or your tone of voice (e.g., stress, annoyance, irritability, etc.).

### MANAGE THE BEHAVIOR

- Identify the triggering event that caused the behavior.
- Rule out pain as the cause of the behavior.
- Schedule appointments or activities when your loved one is most alert and able to process new information or environments.
- Focus on identifying the feelings behind the words or actions.
- Speak slowly and in a soft reassuring tone without getting upset.
- Limit distractions in the environment or shift the focus to another activity to avoid future outbursts.
- Soothe your loved one with a relaxing activity, such as music, massage, or exercise.
- Take a moment for yourself if your loved one is in a safe environment.
- Call 911 if your loved one is unable to calm down—and tell first responders that your loved one has a dementia which causes them to act aggressively.

## PARANOIA<sup>8</sup>

### UNDERSTAND THE BEHAVIOR

Your loved one may become suspicious of those around them, accuse them of theft, infidelity, or other inappropriate behavior, and believe that you and other family members are out to get them. Although not grounded in reality, the situation is very real to the person with Alzheimer's disease or other dementias. Keep in mind that your loved one is trying to make sense of his or her world and that the disease is causing this behavior. Try not to take offense.

### IDENTIFY THE CAUSE

In mid- to late-stage Alzheimer's disease, increasing confusion and memory loss can contribute to your loved one's delusions (false beliefs) and paranoia.

### MANAGE THE BEHAVIOR

- Help others understand your loved one's changing behaviors and that suspicions and false accusations are caused by the disease, not them.
- Listen to his or her reality and reassure your loved one that you care.
- Allow your loved one to express ideas and acknowledge his or her opinions—without trying to convince them.
- Offer brief, but simple explanations that don't overwhelm your loved one.
- Engage your loved one in another activity to switch his or her focus.
- Purchase two or three of the same item in case your loved one continually searches for that "lost" item (e.g., a wallet).
- Get outside help if your loved one is having severe delusions and you fear self-harm or caregiver harm.

## SLEEP ISSUES<sup>9</sup>

### UNDERSTAND THE BEHAVIOR

Those with Alzheimer's disease and other dementias may experience difficulty sleeping or increased confusion, anxiety, agitation, pacing, and disorientation beginning at dusk and continuing throughout the night ("sundowning").

### IDENTIFY THE CAUSE

Although the exact cause is unknown, it's believed that these changes result from the disease's impact on the brain. Other factors that may contribute include:

- Mental and physical exhaustion from an unfamiliar or confusing environment.
- An upset in the "internal body clock," causing a mix-up between day and night.

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8. Alzheimer's Association, alz.org. <https://www.alz.org/help-support/caregiving/stages-behaviors/suspicious-delusions>, retrieved 09/16/2022.

9. Alzheimer's Association, alz.org. <https://www.alz.org/help-support/caregiving/stages-behaviors/sleep-issues-sundowning>, retrieved 09/16/2022.

- Reduced lighting that can increase shadows, causing your loved one to misinterpret what they see.
- Nonverbal behaviors of others, especially stress or frustration.
- Disorientation due to the inability to separate dreams from reality when sleeping.
- Less need for sleep, which is common among older adults.

## MANAGE THE BEHAVIOR

- Get plenty of rest so you're less likely to exhibit unintended nonverbal behavior.
- Schedule appointments, trips, and bathing when your loved one is most alert.
- Encourage regular times for waking up, eating meals, and going to bed.
- Encourage walks or time outside in the sunlight, as appropriate.
- Keep track of what happens before sundowning events and try to identify triggers.
- Reduce stimulation—e.g., watching TV, doing chores, listening to loud music, etc.—during the evening hours.
- Offer a larger meal at lunch and a lighter meal for dinner.
- Reduce your loved one's confusion by keeping the home well lit in the evening.
- Keep from physically restraining your loved one as it can worsen his or her agitation.
- Find soothing activities that your loved one will enjoy, such as listening to calming music or watching a favorite movie.
- Take a walk to help reduce your loved one's restlessness.
- Talk to the doctor about the best times of day to give your loved one medication.
- Limit daytime naps if there are issues with sleeping at night.
- Reduce or avoid alcohol, caffeine, and nicotine, which can disturb sleep.
- Talk to a doctor about physical ailments that can cause or worsen sleep problems.

Finally, if your loved one awakens and is upset, approach in a calm manner, remind him or her of the time, and find out if he or she needs anything. Reassure your loved one that everything is alright and, if needed, supervise him or her if they need to pace back and forth.

## DIETARY ISSUES<sup>10</sup>

### UNDERSTAND THE BEHAVIOR

Regular, nutritious meals can become challenging for people in the middle and late stages of Alzheimer's disease. They may become overwhelmed with too many food choices, forget to eat, or believe that they've already eaten.

9. Alzheimer's Association, alz.org, <https://www.alz.org/help-support/caregiving/stages-behaviors/sleep-issues-sundowning>, retrieved 09/16/2022.

10. HelpGuide.org, <https://www.helpguide.org/articles/alzheimers-dementia-aging/alzheimers-behavior-management.htm>, retrieved 09/16/2022.

## IDENTIFY THE CAUSE

Possible causes of poor appetite include:

- No longer recognizing the foods on their plates.
- Inability to tell you about their poor fitting dentures or other dental problems.
- New medications or changes in dosages for existing medications.
- Lack of physical activity or exercise.
- Decreased sense of smell and taste.

## MANAGE THE BEHAVIOR

- Prepare your loved one's favorite foods.
- Limit distractions by serving meals in quiet settings.
- Keep table settings simple.
- Use contrasting colors to help distinguish food from the plate or table (e.g., white plate on a red placemat).
- Check temperatures to ensure food and beverages are cool enough to eat.
- Offer one food at a time as your loved one may have difficulty choosing.
- Be flexible with food preferences as they may have changed.
- Allow plenty of time to eat—it may take an hour or more for your loved one to eat.
- Eat with others as it may encourage your loved one to eat.
- Consider serving several "breakfasts" if your loved one keeps asking about breakfast.
- Grind foods, cut them into bite-size pieces, or serve soft foods that aren't hard to chew or swallow.
- Avoid foods that are hard to chew thoroughly and watch for signs of choking.
- Learn the Heimlich maneuver in case of an emergency.

## REPETITION<sup>11</sup>

### UNDERSTAND THE BEHAVIOR

Because people with Alzheimer's disease gradually lose the ability to communicate, they may do or say the same thing over and over or re-do something that has just been done. It's important to regularly monitor their comfort and anticipate their needs.

### IDENTIFY THE CAUSE

Deteriorating brain cells cause a decline in the individual's ability to make sense of the world. Your loved one may not remember that she or he has just asked a question or completed a task. In most cases, he or she is likely seeking comfort, security, and familiarity or trying to express a concern or ask for help.

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11. Alzheimer's Association, alz.org, <https://www.alz.org/help-support/caregiving/stages-behaviors/repetition>, retrieved 09/16/2022.



## MANAGE THE BEHAVIOR

- Look for a reason behind the repetition—certain times, people, environment, etc.
- Focus on how your loved one is feeling rather than on what he or she is doing.
- Turn a repetitive action or behavior into a useful activity (e.g., if they're rubbing their hand across the table, ask for help with dusting).
- Stay calm and be patient—he or she likely doesn't remember asking the same question.
- Answer your loved one, even if you have to repeat it several times.
- Reduce boredom by engaging your loved one in an activity.
- Use memory aids—notes, calendars, or photographs—as reminders.
- Accept your loved one's behavior and find ways to work with it.

## HALLUCINATIONS<sup>12</sup>

### UNDERSTAND THE BEHAVIOR

When a person with Alzheimer's disease or other dementias hallucinates, he or she may see, hear, smell, taste or feel something that isn't there. Some hallucinations involve ordinary visions of people, situations, or objects from the past, while others can be truly frightening. NOTE: There are other causes of hallucinations—schizophrenia, infections, pain, substance abuse, side effects of medication, etc.—so it's important to see a doctor to rule out any other issues.

### IDENTIFY THE CAUSE

Hallucinations are false perceptions of objects or events involving the senses, caused by Alzheimer's disease-related changes within the brain—often in later stages of the disease. For example, your loved one may hear a long-ago friend that you can't see or see insects crawling on his or her hand. Unless the hallucination is frightening to them, it may not be necessary to use the strategies below.

### MANAGE THE BEHAVIOR

- Calmly assure your loved one that you're there and that they're OK, if the hallucination appears to be frightening them.
- Gently pat their hand to get their attention which may help reduce the hallucination.
- Acknowledge your loved one's feelings and try to uncover what the hallucination means to him or her.
- Distract your loved one by suggesting a walk, moving to another room, starting a conversation, or turning on some music.
- Be honest if your loved one asks if you see something, but don't deny that it's there.
- Eliminate any sounds that might be misinterpreted, such as noise from a television or an air conditioner.

- Turn on lights to reduce shadows, reflections, or distortions caused by dim lighting.
- Cover or remove mirrors if your loved one sees someone other than themselves.

## WANDERING<sup>13</sup>

### UNDERSTAND THE BEHAVIOR

It's common for those living with dementia to wander or become lost or confused about their location—and it can happen at any stage of the disease. Some 60% will wander at least once, while many do so repeatedly. Wandering can be dangerous, even life-threatening, which puts added stress on caregivers and family.

Everyone with Alzheimer's disease and other dementias is at risk for wandering, but there are signs to watch for. Take extra care if your loved one:

- Returns from a regular walk or drive later than usual.
- Forgets how to get to familiar places.
- Talks about fulfilling former obligations, such as going to work.
- Tries to or wants to "go home" even when at home.
- Becomes restless, paces, or makes repetitive movements.
- Has difficulty finding familiar places, such as the bathroom or bedroom.
- Asks the whereabouts of past friends and family.
- Acts as if doing a hobby or chore, but nothing gets done.
- Appears lost in a new or changed environment.
- Becomes nervous or anxious in crowded areas, such as markets or restaurants.

### IDENTIFY THE CAUSE

Alzheimer's disease and other dementias cause people to lose their ability to recognize familiar places and faces.

### MANAGE THE BEHAVIOR

If your loved one is in the early stage of the disease, the following tips may help reduce the risk of wandering or getting lost:

- Determine a set time each day to check in with each other.
- Review your loved one's scheduled activities and appointments for the day together.
- Find a companion to sit with your loved one if you're not available.
- Consider alternative transportation options if driving safely or getting lost becomes a concern.

These suggestions may help reduce the risk of wandering for someone living with Alzheimer's disease or other dementias—but they are no guarantee:

- Enroll in a nationwide emergency response service that helps safely return those who wander or have a medical emergency.
- Create opportunities for your loved one to engage in structured, meaningful activities throughout the day.
- Identify the time of day your loved one is most likely to wander and plan activities during this time.
- Ensure basic needs are met, including toileting, nutrition and hydration.
- Reduce (not eliminate) liquids up to two hours before bedtime so your loved one won't have to find and use the bathroom during the night.
- Involve your loved one in daily activities, such as folding laundry or preparing dinner. Learn about creating a daily plan.
- Calmly reassure the person if he or she feels lost, abandoned, or disoriented.
- Consider using a GPS device to help your loved one if they get lost (if still driving).
- Remove access to car keys if your loved one is no longer able to drive.
- Avoid places that can cause confusion or disorientation, such as shopping malls.
- Supervise your loved one if new surroundings cause confusion, disorientation, or agitation.
- Ask friends, family, and neighbors to alert you if they see your loved one wandering, lost, or dressed inappropriately.
- Keep a recent, head-and-shoulders photo of your loved one on hand to give to police, should the need arise.
- Know your loved one's neighborhood and identify potentially dangerous areas, such as bodies of water, open stairwells, dense foliage, tunnels, bus stops, and heavily trafficked roads.
- Create a list of places your loved one might wander to—past workplaces, favorite restaurants, places of worship, and previous homes.

Finally, as the disease progresses and/or the risk for wandering increases, assess your loved one's living environment and take steps to eliminate situations that may present a danger or safety hazard. (See Resources for the Alzheimer's Association Home Safety Checklist)

## MAKE A PLAN

Having a plan in place in case your loved one does wander or gets lost not only helps you know what to do in case of an emergency, but it also helps minimize stress.

If your loved one does go missing, begin search efforts immediately and notify police if your loved one isn't located within 15 minutes. Be sure to tell them that your loved one has Alzheimer's disease or other dementias.

## REACH OUT AND CONNECT/SHARE YOUR EXPERIENCES

Finally, regardless of the stage of Alzheimer's disease that your loved one is in or what behaviors they're experiencing, finding a support group or online community can help you connect with others going through similar changes with their loved ones. It's an opportunity for you to share the strategies that have worked for you and get new strategies from other caregivers like yourself.

The Alzheimer's Association has an online community and message boards for anyone affected by Alzheimer's disease or other dementias (ALZConnected.org). They also help you find a peer-led or professionally led support group in your area.

You are not alone. There are 5.8 million people in the United States with Alzheimer's disease or a related dementia and even more friends and family who care about them. Reach out for help today.

## RESOURCES

Alzheimer's Association

1-800-272-3900 (24-hour helpline)

Free online community: ALZConnected.org

Find a support group: <https://www.alz.org/help-support/community/support-groups>

<https://www.alz.org>

Alzheimer's and related Dementias Education and Referral Center (ADEAR)

1-800-438-4380

<https://www.nia.nih.gov/health/about-adear-center>

Alzheimer's Foundation of America

1-866-232-8484

<https://alzfdn.org/caregiving-resources/>





**THE WOODLANDS**  
AT CANTERFIELD

901 ANGLE TARN, WEST DUNDEE, IL 60118

224.802.4388

[WWW.WOODLANDSATCANTERFIELD.COM](http://WWW.WOODLANDSATCANTERFIELD.COM)

