Problem solving when caring for clients with Dementia/Alzheimer's Disease who exhibit challenging behaviors.

Anxiety and Agitation.

A person with Alzheimer's may feel anxious or agitated. He or she may become restless, causing a need to move around or pace, or become upset in certain places or when focused on specific details.

Possible causes of agitation

Anxiety and agitation may be caused by a number of different medical conditions, medication interactions or by any circumstances that worsen the person's ability to think. Ultimately, the person with dementia is biologically experiencing a profound loss of their ability to negotiate new information and stimulus. It is a direct result of the disease.

Situations that may lead to agitation include:

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

Tips to help prevent agitation

To prevent or reduce agitation:

- **Create a calm environment.** Remove stressors. This may involve moving the person to a safer or quieter place, or offering a security object, rest or privacy. Try soothing rituals and limiting caffeine use.
- **Avoid environmental triggers.** Noise, glare and background distraction (such as having the television on) can act as triggers.
- **Monitor personal comfort.** Check for pain, hunger, thirst, constipation, full bladder, fatigue, infections and skin irritation. Make sure the room is at a comfortable temperature. Be sensitive to fears, misperceived threats and frustration with expressing what is wanted.
- **Simplify tasks and routines.**
- **Provide an opportunity for exercise.** Go for a walk. Garden together. Put on music and dance.

How to respond

Do: Back off and ask permission; use calm, positive statements; reassure; slow down; add light; offer guided choices between two options; focus on pleasant events; offer simple exercise options, try to limit stimulation.
Say: May I help you? Do you have time to help me? You're safe here. Everything is under control. I apologize. I'm sorry that you are upset. I know it's hard. I will stay with you until you feel better.

- **Listen to the frustration.** Find out what may be causing the agitation, and try to understand.
- **Provide reassurance.** Use calming phrases such as: "You're safe here;" "I'm sorry that you are upset;" and "I will stay until you feel better." Let the person know you are there.
- **Involve the person in activities.** Try using art, music or other activities to help engage the person and divert attention away from the anxiety.
- **Modify the environment.** Decrease noise and distractions, or relocate.
- **Find outlets for the person's energy.** The person may be looking for something to do. Take a walk or go for a car ride.
- **Check yourself.** Do not raise your voice, show alarm or offense, or corner, crowd, restrain, criticize, ignore or argue with the person. Take care not to make sudden movements out of the person's view.
- **See the doctor.** See the person with dementia's primary care physician to rule out any physical causes or medication-related side effects.
- **Share your experience with others.** Join ALZConnected, our online support community and message boards, and share what response strategies have worked for you and get more ideas from other caregivers.

Depression.

Identifying depression in someone with Alzheimer's can be difficult, since dementia can cause some of the same symptoms. Examples of symptoms common to both depression and dementia include:

- Apathy
- Loss of interest in activities and hobbies
- Social withdrawal
- Isolation
- Trouble concentrating
- Impaired thinking

In addition, the cognitive impairment experienced by people with Alzheimer's often makes it difficult for them to articulate their sadness, hopelessness, guilt and other feelings associated with depression.

Depression in Alzheimer's doesn't always look like depression in people without Alzheimer's. Here are some ways that depression in a person with Alzheimer's may be different:

- May be less severe
- May not last as long and symptoms may come and go
- The person with Alzheimer's may be less likely to talk about or attempt suicide

As a caregiver, if you see signs of depression, discuss them with the primary doctor of the person with dementia. Proper diagnosis and treatment can improve sense of well-being and function.

Diagnosing depression with Alzheimer's disease

There is no single test or questionnaire to detect depression. Diagnosis requires a thorough evaluation by a medical professional, especially since side effects of medications and some medical conditions can produce similar symptoms.

An evaluation for depression will include:

- A review of the person's medical history
- A physical and mental examination
- Interviews with family members who know the person well

Because of the complexities involved in diagnosing depression in someone with Alzheimer's, it may be helpful to consult a geriatric psychiatrist who specializes in recognizing and treating depression in older adults. Ask your doctor for a referral.

The National Institute of Mental Health established a formal set of guidelines for diagnosing the depression in people with Alzheimer's. Although the criteria are similar to general diagnostic standards for major depression, they reduce emphasis on verbal expression and include irritability and social isolation.

For a person to be diagnosed with depression in Alzheimer's, he or she must have either depressed mood (sad, hopeless, discouraged or tearful) or decreased pleasure in usual activities, along with two or more of the following symptoms for two weeks or longer:

- Social isolation or withdrawal
- Disruption in appetite that is not related to another medical condition

- Disruption in sleep
- Agitation or slowed behavior
- Irritability
- Fatigue or loss of energy
- Feelings of worthlessness or hopelessness, or inappropriate or excessive guilt
- Recurrent thoughts of death, suicide plans or a suicide attempt

Treating depression

Getting appropriate treatment for depression can significantly improve quality of life.

The most common treatment for depression in Alzheimer's involves a combination of medicine, counseling, and gradual reconnection to activities and people that bring happiness. Simply telling the person with Alzheimer's to "cheer up," "snap out of it" or "try harder" is seldom helpful. Depressed people with or without Alzheimer's are rarely able to make themselves better by sheer will, or without lots of support, reassurance and professional help.

Non-drug approaches

- Support groups can be very helpful, particularly an early-stage group for people with Alzheimer's who are aware of their diagnosis and prefer to take an active role in seeking help or helping others; counseling is also an option, especially for those who aren't comfortable in groups.
- Schedule a predictable daily routine, taking advantage of the person's best time of day to undertake difficult tasks, such as bathing.
- Make a list of activities, people or places that the person enjoys and schedule these things more frequently.
- Help the person exercise regularly, particularly in the morning.
- Acknowledge the person's frustration or sadness, while continuing to express hope that he or she will feel better soon.
- Celebrate small successes and occasions.
- Find ways that the person can contribute to family life and be sure to recognize his or her contributions.
- Provide reassurance that the person is loved, respected and appreciated as part of the family, and not just for what she or he can do now.
- Nurture the person with offers of favorite foods or soothing or inspirational activities.
- Reassure the person that he or she will not be abandoned.

Medication to treat depression in Alzheimer's

There are several types of antidepressants available to treat depression. Antidepressants

called Selective Serotonin Reuptake Inhibitors (SSRIs) are often used for people with Alzheimer's and depression because they have a lower risk than some other antidepressants of causing interactions with other medications.

As with any medication, make sure to ask about risks and benefits, as well as what type of monitoring and follow-up will be needed.

Hallucinations

When a person with Alzheimer's or other dementia hallucinates, he or she may see, hear, smell, taste or feel something that isn't there. Some hallucinations may be frightening, while others may involve ordinary visions of people, situations or objects from the past.

Understanding hallucinations

Hallucinations are false perceptions of objects or events involving the senses. These false perceptions are caused by changes within the brain that result from Alzheimer's, usually in the later stages of the disease. The person may see the face of a former friend in a curtain or may see insects crawling on his or her hand. In other cases, a person may hear someone talking and may even engage in conversation with the imagined person.

Alzheimer's and other dementias are not the only cause of hallucinations. Other causes include:

- Schizophrenia.
- Physical problems, such as kidney or bladder infections, dehydration, intense pain, or alcohol or drug abuse.
- Eyesight or hearing problems.
- Medications

Coping strategies

When responding to hallucinations, be cautious. First, assess the situation and determine whether the hallucination is a problem for the person or for you. Is the hallucination upsetting? Is it leading the person to do something dangerous? Is the sight of an unfamiliar face causing the person to become frightened? If so, react calmly and quickly with reassuring words and a comforting touch. Do not argue with the person about what he or she sees or hears. If the behavior is not dangerous, there may not be a need to intervene.

For more coping strategies, join ALZConnected, our online support community where caregivers like you share tips on what has worked for them.

Offer reassurance

- Respond in a calm, supportive manner. You may want to respond with, "Don't worry. I'm here. I'll protect you. I'll take care of you."
- Gentle patting may turn the person's attention toward you and reduce the hallucination.
- Acknowledge the feelings behind the hallucination and try to find out what the hallucination means to the individual. You might want to say, "It sounds as if you're worried" or "I know this is frightening for you."

Use distractions

- Suggest a walk or move to another room. Frightening hallucinations often subside in well-lit areas where other people are present.
- Try to turn the person's attention to music, conversation or activities you enjoy together.

Respond honestly

- If the person asks you about a hallucination or delusion, be honest. For example, if he or she asks, "Do you see him?" you may want to answer with, "I know you see something, but I don't see it." This way, you're not denying what the person sees or hears, but you avoid an argument.

Modify the environment

- Check for sounds that might be misinterpreted, such as noise from a television or an air conditioner.
- Look for lighting that casts shadows, reflections or distortions on the surfaces of floors, walls and furniture. Turn on lights to reduce shadows.
- Cover mirrors with a cloth or remove them if the person thinks that he or she is looking at a stranger.

Sleep issues and Sundowning

Sundowning is increased confusion that people living with Alzheimer's and dementia may experience from dusk through night. Also called "sundowner's syndrome," it is not a disease but a set of symptoms or dementia-related behaviors that may include difficulty sleeping, anxiety, agitation, hallucinations, pacing and disorientation. Although the exact cause is unknown, sundowning may occur due to disease progression and changes in the brain.

Factors that may contribute to trouble sleeping and sundowning

- Mental and physical exhaustion from a full day of activities.
- Navigating a new or confusing environment.
- A mixed-up "internal body clock." The person living with Alzheimer's may feel tired during the day and awake at night.
- Low lighting can increase shadows, which may cause the person to become confused by what they see. They may experience hallucinations and become more agitated.
- Noticing stress or frustration in those around them may cause the person living with dementia to become stressed as well.
- Dreaming while sleeping can cause disorientation, including confusion about what's a dream and what's real.
- Less need for sleep, which is common among older adults.

Tips that may help manage sleep issues and sundowning

- Encourage the person living with dementia to get plenty of rest.
- Schedule activities such as doctor appointments, trips and bathing in the morning or early afternoon hours when the person living with dementia is more alert.
- Encourage a regular routine of waking up, eating meals and going to bed.
- When possible, spend time outside in the sunlight during the day.
- Make notes about what happens before sundowning events and try to identify triggers.
- Reduce stimulation during the evening hours. For example, avoid watching TV, doing chores or listening to loud music. These distractions may add to the person’s confusion.
- Offer a larger meal at lunch and keep the evening meal lighter.
- Keep the home well lit in the evening to help reduce the person’s confusion.
- Try to identify activities that are soothing to the person, such as listening to calming music, looking at photographs or watching a favorite movie.
- Take a walk with the person to help reduce their restlessness.
- Talk to the person's doctor about the best times of day for taking medication.
- Try to limit daytime naps if the person has trouble sleeping at night.
- Reduce or avoid alcohol, caffeine and nicotine, which can all affect the ability to sleep.
- If these suggestions do not help, discuss the situation with the person's doctor.

If the person is awake and upset

- Approach them in a calm manner.
- Find out if there is something they need.

- Gently remind them of the time.
- Avoid arguing.
- Offer reassurance that everything is all right.
- Don't use physical restraint. Allow the person to pace back and forth, as needed, with supervision.

Wandering

Alzheimer's disease causes people to lose their ability to recognize familiar places and faces. It's common for a person living with dementia to wander or become lost or confused about their location, and it can happen at any stage of the disease. Six in 10 people living with dementia will wander at least once; many do so repeatedly. Although common, wandering can be dangerous — even life-threatening — and the stress of this risk weighs heavily on caregivers and family.

Who's at risk for wandering?

Everyone living with Alzheimer's or other dementia is at risk for wandering. Common signs a person may be at risk of wandering include:

- Returning from a regular walk or drive later than usual.
- Forgetting how to get to familiar places.
- Talking about fulfilling former obligations, such as going to work.
- Trying or wanting to "go home" even when at home.
- Becoming restless, pacing or making repetitive movements.
- Having difficulty locating familiar places, such as the bathroom, bedroom or dining room.
- Asking the whereabouts of past friends and family.
- Acting as if doing a hobby or chore, but nothing gets done.
- Appearing lost in a new or changed environment.
- Becoming nervous or anxious in crowded areas, such as markets or restaurants.

Reduce the risk of wandering

The following tips may help reduce the risk of wandering and can bring peace of mind to caregivers and family members; however, these actions cannot guarantee that a person living with dementia won't wander.

- Provide opportunities for the person to engage in structured, meaningful activities throughout the day.

- Identify the time of day the person is most likely to wander (for those who experience "sundowning," this may be starting in the early evening). Plan things to do during this time — activities and exercise may help reduce anxiety, agitation and restlessness.
- Ensure all basic needs are met, including toileting, nutrition and hydration. Consider reducing — but not eliminating — liquids up to two hours before bedtime so the person doesn't have to use and find the bathroom during the night.
- Involve the person in daily activities, such as folding laundry or preparing dinner. Learn about creating a daily plan.
- Reassure the person if he or she feels lost, abandoned or disoriented.
- If the person is still safely able to drive, consider using a GPS device to help if they get lost.
- If the person is no longer driving, remove access to car keys — a person living with dementia may not just wander by foot. The person may forget that he or she can no longer drive.
- Avoid busy places that are confusing and can cause disorientation, such as shopping malls.
- Assess the person's response to new surroundings. Do not leave someone with dementia unsupervised if new surroundings may cause confusion, disorientation or agitation.

For individuals in the early stage of the disease and their care partners, the following strategies may also help reduce the risk of wandering or getting lost:

- Decide on a set time each day to check in with each other.
- Review scheduled activities and appointments for the day together.
- If the care partner is not available, identify a companion for the person living with dementia as needed.

- Consider alternative transportation options if getting lost or driving safely becomes a concern.

Prepare your home

Home Safety Checklist

Download, print and keep the checklist handy to prevent dangerous situations and help maximize the person living with dementia's independence for as long as possible.

As the disease progresses and the risk for wandering increases, assess your individual situation to see which of the safety measures below may work best to help prevent wandering.

- Place deadbolts out of the line of sight, either high or low, on exterior doors. (Do not leave a person living with dementia unsupervised in new or changed surroundings, and never lock a person in at home.)
- Use night lights throughout the home.
- Cover door knobs with cloth the same color as the door or use safety covers.
- Camouflage doors by painting them the same color as the walls or covering them with removable curtains or screens.
- Use black tape or paint to create a two-foot black threshold in front of the door. It may act as a visual stop barrier.
- Install warning bells above doors or use a monitoring device that signals when a door is opened.
- Place a pressure-sensitive mat in front of the door or at the person's bedside to alert you to movement.
- Put hedges or a fence around the patio, yard or other outside common areas.
- Use safety gates or brightly colored netting to prevent access to stairs or the outdoors.
- Monitor noise levels to help reduce excessive stimulation.
- Create indoor and outdoor common areas that can be safely explored.
- Label all doors with signs or symbols to explain the purpose of each room.
- Store items that may trigger a person’s instinct to leave, such as coats, hats, pocketbooks, keys and wallets.
- Do not leave the person alone in a car.

Plan ahead

The stress experienced by families and caregivers when a person living with dementia wanders and becomes lost is significant. Have a plan in place beforehand, so you know what to do in case of an emergency:

- Consider enrolling the person living with dementia in a wandering response service.
- Ask neighbors, friends and family to call if they see the person wandering, lost or dressed inappropriately.
- Keep a recent, close-up photo of the person on hand to give to police, should the need arise.
- Know the person’s neighborhood. Identify potentially dangerous areas near the home, such as bodies of water, open stairwells, dense foliage, tunnels, bus stops and roads with heavy traffic.
- Create a list of places the person might wander to, such as past jobs, former homes, places of worship or a favorite restaurant.

Take action when wandering occurs

When someone with dementia is missing

Begin search-and-rescue efforts immediately. Many individuals who wander are found within 1.5 miles of where they disappeared.

- Start search efforts immediately. When looking, consider whether the individual is right- or left-handed — wandering patterns generally follow the direction of the dominant hand.
- Begin by looking in the surrounding vicinity — many individuals who wander are found within 1.5 miles of where they disappeared.
- Check local landscapes, such as ponds, tree lines or fence lines — many individuals are found within brush or brier.
- If applicable, search areas the person has wandered to in the past.
- If the person is not found within 15 minutes, call 911 to file a missing person's report. Inform the authorities that the person has dementia.