



Indiana Dementia Training for Direct Care Providers

Wandering and Exit Seeking in Dementia

Course Description:

This session is a self-paced learning activity. As many as 6 out of 10 persons with Alzheimer's Disease or other related dementias will wander at some point in their disease process. In the client's home, direct care providers do not control the environment, which makes protecting the client from exit seeking more difficult. It is important to recognize how to lessen the likelihood of exit-seeking and wandering while understanding that, in some instances, pacing may be a person-centered and appropriate method for a client to manage their unease and anxiety. It is up to the home care worker to help adjust the environment in a person-centered way so as to keep the client safe while maintaining as much independence as possible.

Learning Objectives:

- 1. Understand why a client with dementia may wander.*
- 2. Understand how to make appropriate environmental modifications to increase client safety.*
- 3. Develop knowledge of how to determine contributing factors for wandering behaviors.*
- 4. Become familiar with ways to prevent wandering and exit seeking.*
- 5. Learn the process of how to report a client with dementia as missing.*

This activity contains a post-test. You must complete the entire learning activity and test and score an 80% or higher to obtain a certificate of completion. Partial credit will not be given.

Contact Hours: 1 hour, including a required quiz.

According to the Alzheimer's Association, 6 out of 10 people with dementia will wander at some point in their disease process. Wandering can be a safety concern and is one of the more challenging dementia-related behaviors for family and paid caregivers. Unsafe wandering is a big concern, generally occurring in the moderate stage of dementia. In this stage, clients may begin to have problems with judgment, problem-solving, and wayfinding skills. Therefore, they may try to leave the house. Once outside, they may not be dressed for the weather, or they could get lost and be unable to find their way back.

While the exact causes of wandering behavior are not fully understood, it may occur in some individuals searching for something or trying to get back to a place they remember, like a job or favorite destination. In some cases, the person may be attempting to escape an unfamiliar/uncomfortable environment in an attempt to find something familiar, and sometimes people just wander or walk away because they are restless or agitated.



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Other Common Reasons Clients May Wander Include:

Emotions

Those who suffer from dementia experience the severe anxiety associated with not knowing where they are, what they are supposed to be doing, who the people are around them, and perhaps not even their names. Many who experience this disorientation and memory loss spend their time wandering in search of answers. Their fear is often made worse by the inability to express their feelings and needs. A client who is frustrated, anxious, bored, or depressed is more likely to wander. Sedating medications also increase the risk of wandering, resulting in increased confusion.

Dementia-specific changes

Changes in the visual cortex, which occur in one-third to one-half of all people with Alzheimer's type dementia, contribute to the risk of becoming lost. This impairment leads to difficulty interpreting the environment. The environment constantly bombards the brain with ever-changing information. This can make it difficult for a person with dementia who takes longer to process and understand information. Another problem with dementia is that it affects the part of the brain that helps create a mental map of where a person is so that they know how to retrace their steps. But without this mental map ability, a person with dementia can get lost in their own neighborhood or even their own house.

Clients with dementia may be misinterpreting their environment in many ways. They may see shadows and interpret them as dangerous people or animals. Noises and smells can also be misinterpreted and can lead to fear which may make the client try to leave the area.

Other Unmet needs Wandering may signal an unmet need, such as hunger, thirst, constipation, inactivity, need to use the toilet, fatigue, pain, or discomfort, such as uncomfortable seating or mattresses. They may also be in need of social interaction and wander to try to find another person. Finally, they may be seeking physical movement and begin pacing or moving around their environment as a response.

Environment

While a person with a physical disability needs modifications for physical access to their environment, such as ramps, a person with dementia often needs modifications to help them UNDERSTAND their environment.

Cognitively intact people are able to read the environment as to how they should act and what they should do. But cues are often required for cognitively impaired older adults to orient them to a place and to let them understand what they are supposed to do in that place. Without these visible cues, a person is more likely to wander or not recognize common places in their environment. As dementia progresses, however, even common objects and cues may no longer be recognized by the person with dementia which further makes the environment difficult to understand. For example, even if you make the toilet visible by keeping the door to the bathroom open, the person with dementia may not make the connection that the room containing the toilet is the bathroom and may wander looking for the toilet. However, the more cues you provide, the better your chance of creating recognition. You can add signage, pictures, or use color to provide more contrast for the items you wish the client to see. You can increase contrast on a toilet by encouraging the use of a vibrant colored toilet seat or rug so that the toilet stands out.



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Busy patterns or cluttered areas also make the environment more difficult to interpret and confusing for the person with dementia. Lighting that casts shadows can be misinterpreted as other objects and also increase confusion in an environment. This is more likely to happen in the evenings when the sun is setting, and shadows are more likely. If a client is confused or frightened, they may wander.

Prevention is key in helping a client remain safe. One of the first things is to try to identify anything in the environment that may trigger the person to think they need to leave. Things like an umbrella, coat hanging on a hook, or hat can trigger someone to think they need to go out. In addition, try to identify other possible triggers, such as hunger, thirst, the need to go to the bathroom, boredom, or confusion with the current environment. Often, the person with dementia may be trying to find a way to meet their needs, but they get lost in this process.

It may seem like an odd approach, but camouflaging doors and windows can sometimes prevent a client with dementia from finding a way out of their home. Family caregivers might consider painting doors and doorframes the same color as walls or hanging curtains on windows that match the color of the walls. This will help exits blend in with surroundings and make them less “visible” to persons living with dementia. Another optical trick that some family caregivers have used is placing a dark, solid-colored doormat in front of doors leading outside. Something about the visual effects of dementia may cause persons with dementia to perceive the mat as a “hole” in the floor, thereby deterring them from using the door. Also, using tape to create a grid-like pattern on the floor in front of exits or restricted areas may decrease the risk of exiting an area because it gives an unstable appearance with the grid lines.

How to Determine Contributing Factors for Wandering Behaviors

There is no one-size-fits-all solution. Rather becoming skilled at problem-solving is the better approach. Try to understand each individual in each situation. Some useful questions to determine why your client may wish to exit, leave, or pace may include the following:

- Are they taking a new medication or experiencing a new symptom?
- Are they trying to perform a task that may be too complicated or confusing?
- Are they bored?
- Are they too hot or cold?
- Is the area too noisy?
- Are they trying to go somewhere like work, church, or home?
- Does the wandering happen around the same time every day?
- Are they trying to meet a basic need, such as hunger or thirst?
- Are they searching for the bathroom?
- Do they feel lost and scared? Are they looking for a home?
- Do they seem to be experiencing delusions or hallucinations?
- Are there unusual shadows?
- Are there any unusual or distracting patterns that could be misinterpreted? Sometimes those with dementia can misinterpret patterns on couches or curtains for things like bugs or snakes, which can cause agitation.
- Is the environment too cluttered, which may make understanding what the client is supposed to do more difficult?
- Are they anticipating an event, such as a visit from a friend or family member, which may contribute to their worry and contribute to wandering? Many people with dementia get restless or anxious if they are advised of plans ahead of time.



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Steps to Help Prevent Wandering

The key to responding to wandering is person-centered care and knowing your client and their needs and history. Responding to wandering and exit-seeking behaviors effectively can help people with dementia remain as independent as possible in their homes and communities.

When a person with dementia insists on going out, it is often best to go with them. If they are really intent on going out, it is difficult to stop them, and often trying to do so makes things worse. Saying something like, “Oh, I was going that way too, may I join you?” can help diffuse the agitation and upset the person. Another option is to try to distract the person with something. Saying something like, “OK, I know you need to go, but can you help me with something first” may work. Arguing is often not the best response to a person attempting to leave. When agitated, a person with dementia may become aggressive and then leave the residence in fear or anger, making them more likely to be injured.

The timing of wandering is unpredictable, and the abilities can change with the progression of dementia. Functioning and orientation may also fluctuate day-to-day in someone with dementia. Therefore, it is important for you to always be on alert and know that just because the person has not attempted to wander before does not mean they will not start.

There are steps that caregivers can take to help prevent wandering or make it difficult for the person to wander away and including such things as:

Creating a secure environment by...

- Encourage door or window alarms. Something as simple as a bell hung high can help you know if your client is wandering outside.
- Remove access to car or lawnmower.
- Encourage the family to attach doorknob covers to doors that access the outdoors. These will turn without actually opening the door.
- Place signs on important exit doors that say things like STOP and DO NOT ENTER.
- Regular night lights can help someone who has a tendency to wander at night. Night lights reduce disorientation and help prevent falls and accidents. Consider motion-sensor lights.
- Close curtains, so the client is not cued to go outside.
- Camouflage some doors with a screen, curtain, or a painted mural. You can also try to camouflage the doorknob by placing a decorative plant stand at the level of the doorknob.
- Install locks that are difficult to operate and higher up on the doorframe, out of the field of vision or the person’s reach.
- Try to follow the person or offer to walk with them until they are ready to be redirected towards home.
- Do not try to prevent the client from leaving the house once it is clear they are intent on doing so. Research shows that it takes a lot more time to de-escalate a person who is verbally and physically responsive when you are trying to prevent them from leaving home than it does to accompany them outside for 5-15 minutes.

Create a more understandable environment by....

- Speak slowly and gently/try not to say too much at one time. Don’t argue with the person.
- Find meaningful, simple activities, so the person is not bored.



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- If the person is looking to fulfill a basic need, such as toileting, hunger, or thirst, guide the person to the appropriate place. Signs the client may need to go to the bathroom may be fidgeting with clothes or holding onto themselves.
- In the early stages, cues such as signs or pictures can be placed on things such as the bathroom door, so the person can more easily find things.
- Plan daily activities during the time a person tends to wander. This could include an exercise regime, participation in household activities, participation in gardening activities, walks to the store, etc.
- Decrease noise levels in the environment and the number of people interacting with the individual to prevent overstimulation.
- At night time, be sure the bathroom or a commode is easily accessible and visible.
- Use night lights, floor lighting, signs, and familiar objects to assist the person in moving around an area safely, particularly for finding the bathroom at night.
- Reflector tape is helpful around a bathroom door to assist in finding the bathroom.
- Make sure the light is bright enough to help reduce shadows.
- Avoid telling the resident what you DON'T want them to do. If you tell them "Don't go outside," they have to think about outside first and then have to un-think it. This is a complex cognitive process.

Managing restless behavior with...

- Activities to occupy the person's time. Keep activities simple such as having them help with an activity, such as folding laundry or setting the table. You can also sit quietly with the person and listen to music or watch TV.
- Regular physical exercise.
- Try not to say "No, Don't, Can't, Should not...." Try saying, "Let's do this first," "Wouldn't it be fun to..." "What if we..."
- Plan activities during the time of day that the person wanders most.
- Offer the person something they like to eat.
- Ensuring adequate sleep.
- Report behavior changes or increased confusion to your supervisor.
- Sometimes, a rocking chair can help with restless behavior as long as the client is safe to be in a rocking chair.
- Wandering may be due to the person searching for a person, place, or object from the past. Reminiscing about things from the past may be comforting. Photo albums, travel books, and magazines are ways of introducing a reminiscence activity.

What To Do If Your Client is Lost

Clients who have a history of wandering are more likely to wander again. Therefore, if they have wandered, it is important to know where they might have wandered to and as many details as possible to try to prevent a future exiting. It will be important to determine if the client wanders at a specific time of the day and then try to fill that time with activities that the client enjoys. If the client does manage to walk away and you can't find them after 15 minutes, call 911. Tell the police that a person with dementia is lost and then follow their instructions. Immediately call your supervisor to report what is happening. Generally, the law enforcement agency investigating the missing person will determine if a Silver Alert needs to be issued. The Silver Alert is an emergency notification sent to the media and



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public through the Emergency Activation System (EAs) and is a tool to assist in locating a missing person who went missing under unexplained or suspicious circumstances. There must be enough descriptive information for the broadcast to help.

For every additional minute that goes by, the search area broadens. Although common, wandering can be dangerous—if not found within 24 hours, up to half of those who wander risk serious injury or death. Inclement weather, busy roads, and landscape trouble spots pose a greater risk to the wandering individual.

The Source of Search & Rescue Research, Publications, and Training offer the following behavioral profile of the critical wanderer(officer.com):

Those with dementia who wander

- Will usually (89%) be found within one mile of the point last seen; half found within 0.5 miles.
- Will usually be found a short distance from the road (50% within 33 yards).
- May attempt to travel to former residence or favorite place.
- Will not leave many physical clues.
- Only 1% will cry out for help, and only 1% will respond to shouts.
- Will succumb to the environment (hypothermia, drowning, and dehydration).
- Will go until stuck; appear to lack the ability to turn around.
- Will usually be found in a creek or drainage and/or caught in briars/bushes (63%).
- Leaves own residence or nursing home, possibly with the last sighting on a roadway. May cross or depart from roads (67%).
- Commonly has coexisting medical problems that limit mobility.
- Has a previous history of wandering (72%).

Technology may now be an option for families to keep those with dementia safe, and the following are utilized by many to lessen the worry about their loved one wandering away. You may want to encourage the family of a client who wanders to investigate one of the following programs.

Safe Return Program

Consider encouraging the client's family to enroll in the Alzheimer's Association's Safe-Return Program. As part of this program, the person with Alzheimer's disease wears a bracelet with a toll-free number and code. The toll-free number may be called from anywhere in North America, and the code is used to identify the person and alert their family of the person's whereabouts.

GPS Tracking

Global Position System tracking devices can quickly locate someone with dementia who has wandered. Tiny GPS monitors fit in jewelry, watches, shoe insoles, or attached to clothing. Other options are smartphone GPS, though this is only useful if your client carries a smartphone.

Alarm Devices

Alzheimer's door alarms use sensors that sound an alarm if certain doors are opened. The devices can also be used on windows and cabinet doors. There are also bed alarms that beep and alert caregivers if a person with dementia is getting out of bed or a chair. In addition, there are floor mats with alarms that are triggered when a person walks on them.



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Medical Alert Systems

Medical alert systems, or Personal Emergency Response Systems (PERS), are commonly thought of as devices used in the event of a fall, but they also track movements in the home and include GPS tracking in case of wandering.

Instead of preventing a person from wandering, sometimes it may be better to provide a safe and supervised place in the home or yard for walking or pacing. Going for walks together during the day may also help curb the impulse in the evenings when many experience symptoms of increased confusion and try to exit.

Even if your client does not wander during the day, they may have more issues once the sunsets. This may be caused by inactivity during the day, too much sleep during the day, delirium, inability to separate dreams from reality, or the inability to appreciate the time. Sometimes a person with dementia will awaken in the night and may believe it is time to get up and dress.

Resources:

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Officer.com. Missing Elderly at Risk. <https://www.officer.com/home/article/10250438/missing-elderly-at-risk>. Retrieved 11/8/21