

Responding to the Wandering and Exit-seeking Behaviors of People with Dementia

Jane Tilly, DrPH
Office of Supportive and Caregiver Services
Administration on Aging
Administration for Community Living

May 2015

The views expressed in this paper are those of the authors and not necessarily those of the Administration for Community Living or the U.S. Department of Health and Human Services.

Responding to the Wandering and Exit-seeking Behaviors of People with Dementia

Introduction

About 5 million people in the United States have dementia.¹ In addition to the estimated 5 million Americans aged 65 years and older with dementia, about 200,000 people under age 65 may have the condition.² Many of those under age 65 with dementia include people with intellectual disabilities. For example, people with Down syndrome are very likely to acquire Alzheimer's disease as they age; about half of them have it when they reach their 60s.³ Age is a major risk factor for dementia, so researchers expect that the number of people living with the condition and needing home and community-based services (HCBS) will grow as the U.S. population ages.

At some point during the course of their disease, people with dementia may wander or try to leave their home without a companion, a behavior often called exit-seeking. Although there are no reliable estimates of the percentage of people who do this, some experts say that more than half of people with dementia will wander at some point during the course of their disease. Wandering can be a safety concern for the person and is one of the more challenging dementia-related behaviors for family and paid caregivers.

People with dementia who wander are moving about in ways that may appear aimless but often have purpose.⁴ People may wander in response to an unmet basic need like human contact, hunger, or thirst; a noisy or confusing environment; or because they are experiencing some type of distress, like pain or the need to use the toilet. Wandering can be helpful or dangerous, depending on the situation. Although people who wander may gain social contact, exercise, and stimulation, they can also become lost or exhausted.

While the research literature on wandering and exit-seeking is limited, it does address methods of responding to these behaviors. The key to responding to wandering is person-centered care, where knowing people and their needs and history helps caregivers anticipate ways to meet needs and prevent injury for those who wander. In addition, the literature describes techniques that may help keep people with dementia from leaving their environments in an unsafe manner.

Responding to wandering and exit-seeking behaviors effectively could help people with dementia remain as independent as possible in their homes and communities and help relieve caregiver stress.

¹ Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*, 80(19), 1778–1783.

² Okura, T., Plassman, B. L., Steffens, D. C., Llewellyn, D. L., Potter, G. G., & Langa, K. M. (2011). Neuropsychiatric symptoms and the risk of institutionalization and death: The aging, demographics, and memory study. *Journal of the American Geriatrics Society*, 59, 473–481.

³ National Down Syndrome Society. (no date) *Aging and Down syndrome, health and well-being guidebook*.

⁴ Tilly, J., & Reed, P., (2009) *Dementia Care Practice Recommendations for Assisted Living and Nursing Homes, Phases 1 & 2*. Alzheimer's Association.

This issue brief:

- Discusses person-centered approaches to meeting people’s needs and evidence about the effectiveness of person-centered services for people with dementia.
- Summarizes evidence and practice recommendations related to implementing person-centered care in the context of responding to wandering and exit-seeking behaviors.
- Provides an appendix with techniques that Administration for Community Living (ACL) dementia grantees know about or have used to address wandering concerns.

Evidence contained in this issue brief is based on an Administration for Community Living (ACL) review of dementia care literature and related practice recommendations and responses to a call to ACL grantees to describe techniques for responding to wandering behavior.

Evidence about Person-centered Care for People with Dementia

Research shows that applying person-centered principles and practices to assessment, planning, and delivery of services can help family and paid caregivers better serve people with dementia, including those who wander. One literature review describes person-centered care principles for people with dementia:⁵

- Understand that the individual in people with dementia is increasingly hidden rather than lost.
- Acknowledge the personhood of people with dementia in providing services.
- Personalize the individual’s care and surroundings.
- Involve the individual with dementia in decision-making.
- Interpret behavior from the person’s viewpoint.
- Ensure that the individual-caregiver relationship is as important as the care tasks.

A literature review on person-centered interventions for people with dementia concluded that, “Person-centered interventions are associated with positive influences on staff outcomes (satisfaction and capacity to provide individualized care); improvement in the psychological status of residents (lower rates of boredom and feelings of helplessness); and reduced levels of agitation in residents with dementia.”⁶

An experiment comparing person-centered care for those with dementia to usual care found less agitation among those who received person-centered service, which persisted for at least 4 months after the experiment ended.⁷ In a pre-post test of the effects of implementing person-

⁵ Edvardsson, D., Winblad, B., & Sandman, P.O. (2008). Person-centered care of people with severe Alzheimer’s disease: current status and ways forward. *Lancet Neurology*, 7, 362-367

⁶ Brownie, S., & Nancarrow, S. (2013). Effects of person-centered care on residents and staff in aged-care facilities: A systematic review. *Clinical Interventions in Aging*, (8), 1-10.

⁷ Chenoweth, L., King, M.T., Jeon, Y-H., Brodaty H., Stein-Parbury, J., Norman, R., Haas, M., & Luscombe, G. (2009). Caring for aged care resident study (CADRES) of person-centered care, dementia-care mapping, and usual care in dementia: A cluster-randomised trial. *Lancet Neurology*, 8, 317-325.

centered dementia care in Sweden staff reported delivering more person-centered care that was better for residents.⁸

The general literature related to person-centered care for people with dementia shows that this group likely receives better care when caregivers use person-centered care principles.

Applying these principles to wandering and exit-seeking means that caregivers are likely to provide better services and supports when they:

1. Know the personal history of the individual with dementia.
2. Know the person's current health condition and remaining abilities.
3. Know the conditions that trigger wandering or exit-seeking, their history and background
4. Try responses to wandering and exit-seeking that respond to the person's unique circumstances.

The effectiveness of person-centered care can be demonstrated through the example of an assisted living facility resident who was entering other residents' apartments without permission and taking or leaving papers there. Staff knew that the resident had worked as a mail carrier so they placed papers and envelopes on tables along the path the resident usually walked. The resident began picking up and leaving papers on these tables and greatly reduced the unwanted visits to other residents' apartments.

Wandering and Exit-seeking

Researchers and practitioners have put person-centered care and environmental design principles to work in responding to wandering or exit-seeking behaviors that lead to problems for individuals with dementia. The care goals⁹ are to:

- Encourage, support, and maintain a person's mobility and choice, enabling him or her to move about safely and independently.
- Ensure that causes of wandering are assessed and managed, with particular attention to unmet needs.
- Prevent unsafe wandering or exit-seeking.

The dementia care research and practice literature recommends specific approaches to responding to wandering.¹⁰ They generally involve the following:

- Assessing the patterns, frequency, and triggers for wandering through direct observation and by talking with people with dementia and their families or friends.
- Using this baseline information to develop a person-centered plan to address these triggers, implementing the plan, and measuring its impact.

⁸ Edvardsson, D., Sandman, P.O., & Borell, L. (2014). Implementing national guidelines for person-centered care of people with dementia in residential aged care: Effects on perceived person-centeredness, staff strain, and stress of conscience. *International Psychogeriatrics*, 26(7), 1171-1179.

⁹ Tilly, J., & Reed, P., (2009) Alzheimer's Association.

¹⁰ Tilly, J., & Reed, P., (2006) *Falls, Wandering, and Physical Restraints: Interventions for Residents with Dementia in Assisted Living and Nursing Homes*. Alzheimer's Association. Tilly, J., & Reed, P., (2009) Alzheimer's Association.

- Using periodic assessments to update information about a person’s wandering and adjust the person-centered plan as necessary.
- Using “environmental design” and other strategies to address common causes of unsafe wandering, for example:
 - Eliminating overstimulation, such as visible doors that people use frequently; noise; and clutter.
 - Preventing under-stimulation by offering activities that engage the interest of people with dementia. Activities could include music, art, physical exercise, mental stimulation, therapeutic touch, pets, or gardening.
 - Providing a safe, uncluttered path for people to wander that has points of interest and places to rest.
 - Using signage to orient the individual to the environment, such as indicating where toilets and bedrooms are.
 - Disguising exit doors using murals or covering door handles as safety codes permit.
 - Using technological solutions as part of a person-centered plan to alert others so that they can reduce the risks associated with a person’s exit-seeking.
 - Recommending that people who may wander unsafely carry identification with their name and the service provider’s location and contact information.
 - Creating a lost-person plan that describes roles and responsibilities when an individual has exited in an unsafe manner.
 - Evaluating each lost-person incident to make revisions to person-centered care plans or to environmental design as necessary.

Practice Recommendations and Related Resources¹¹

Several groups have developed practice recommendations related to person-centered assessment and planning, which can be used to address wandering and exit-seeking behaviors. Other resources are specific to wandering. Following are resources that are available free of charge.

The U.S. Administration for Community Living has an issue brief and a toolkit available on dementia-capable home and community service systems, which include information about person-centered services and links to many resources. These items are available at http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx.

The U.S. Department of Veterans Affairs has several resources devoted to wandering and exit-seeking:

- Staff Educational Toolkit on Wandering for Community Living Centers: http://www.audio.va.gov/visn8/MP4/Managing_HD_YouTube_HD_1080p.mp4
- Satellite broadcast on Dementia: Getting Lost in the Community: http://www.audio.va.gov/visn8/MP4/Dementia_LOST_SD_YouTube-Vimeo_SD_480p.mp4

¹¹ References to nonfederal government sources or sites on the Internet are provided as a service and do not constitute or imply endorsement of these organizations or their programs by ACL or the U.S. Department of Health and Human Services. URL addresses were current as of the date of this publication.

The Alzheimer's Association has person-centered, dementia care practice recommendations based on literature reviews and expert consensus-building processes. All recommendations and literature reviews are available at: http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp. For recommendations on falls, wandering, and physical restraints, see Residential Living (Phase 1 and 2).

The University of North Carolina and the Center on Excellence in Assisted Living have a resource called *Toolkit for Person-Centeredness in Assisted Living – An Informational Guide and Questionnaires of Person-centered Practices in Assisted Living (PC-PAL)* available at http://www.shepscenter.unc.edu/news_release/new-free-questionnaires-can-improve-care-quality-life-older-adults-assisted-living-person-centered-practices/.

The Down Syndrome Society has information caregivers can use to address the unique needs of this population available at: <http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease>. Additional information on dementia practice recommendations to assist people with Down syndrome can be found at the website for the National Task Group on Intellectual Disabilities and Dementia Practices: <http://aadmd.org/ntg>.

See [Appendix 1](#) for a collection of ideas that ACL dementia grantees and their community partners know about or have used when people with dementia wander.

Conclusions

Wandering and exit-seeking are typical behaviors for many people with dementia at some time during the course of their disease. These behaviors can be among the most challenging for family and paid caregivers. The research literature and evidence-based dementia care practice recommendations point to a person-centered response to wandering. This approach first involves getting to know the person with dementia, and the events or conditions that trigger wandering or exit-seeking. Next, caregivers need to be creative in finding individual care or environment-based responses to wandering that promote a person's freedom of movement and safety and reduce unmet needs. There are many free resources available to help caregivers be creative in these ways.

Appendix 1

ACL Grantee Techniques for Coping with Wandering and Exit-Seeking

Background: The Administration for Community Living (ACL) requested that its National Alzheimer’s and Dementia Resource Center ask current and past ACL grantees and community partners about innovative methods or programs for managing unsafe wandering and exit-seeking when it occurs among people with dementia in community settings. This document contains ideas from state grantees.¹²

California

“IDEA!” is a strategy that can be used by adult day care centers or assisted living facility staff to address wandering. IDEA! is a three-step strategy to help caregivers understand why a challenging behavior is happening and how to address it. The process includes the following:

Identifying the problem/challenging behavior

- What is the challenging behavior?

Educating caregivers

- Understand the cause of the behavior
 - Health: Is the person taking a new medication, getting sick, or in pain?
 - Environment: Is it too noisy? Is it too hot? Is the place unfamiliar?
 - Task: Is the task too hard? Are there too many steps? Is it something new?
 - Communication: Is it hard for the person to speak or understand?
- Understand the meaning of the behavior to the person
 - Does the person feel like he or she is being treated like a child?
 - Are there things that remind the person of unhappy experiences?
 - Does the person feel a sense of insecurity, discomfort, or boredom?

Adapt

- Try different things. Pay attention to the person’s feelings. Practice being calm, gentle, and reassuring.
- Distract or redirect by:
 - Offering the person something he or she likes to eat
 - Turning on a TV show or music
 - Asking the person for his or her help with a simple activity
 - Leading the person to a different room

¹² Note that these ideas are provided as a service and do not constitute or imply endorsement of them, or the organizations or programs that supplied the ideas, by ACL or the U.S. Department of Health and Human Services.

- Address the cause or triggers of the behavior
 - Keep tasks and activities simple
 - Keep the home as quiet and calm as possible
 - 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

Massachusetts

Massachusetts has just completed a pilot project of 12 communities involving partnerships among local police departments, Councils on Aging, Area Agencies on Aging, and the Alzheimer's Association to register into a police database people at risk of wandering. The purpose of the project is to eliminate the scrambling for up-to-date photos, likely destinations, etc. that otherwise would occur during the first few hours after a person with dementia is determined to be missing.

Nevada

One way to address wandering behaviors is using crowd-control stanchions like those used in movie theaters, which can be set up in front of exit doors; the wandering person will stop at the barrier. Sometimes the person with dementia may want to stand and hold the rope or rest his or her hand on the pole, but the person generally will not go past the stanchion.

Stop signs or U-turn signs may become less effective if they remain in place all the time. Effectiveness may increase if the signs are used only when needed.

Another strategy is the Target Behavior Plan (TBP), which may work in an adult day care setting or something similar. It requires some staff training and an understanding of the individual's history. A behavior such as wandering is triggered by something the person with dementia is unable to express or in some cases of wandering, attempting to escape an unfamiliar/uncomfortable environment in an attempt to find something familiar. TBP looks at the Who, What, When, Where, and Why of the wandering and then builds a plan to address the behavior. A few of the questions to ask when developing a TBP include the following:

- What is the behavior?
- Why is this behavior a problem?
- How would you like this behavior to change?
- Why do you think this behavior happens?
- When does the behavior happen?
- Where does the behavior happen?
- Who is around when the behavior occurs?
- Have you noticed any pattern in the behavior?
- Additional information (such as physical problems like hearing or vision)

Here is a very simple example: Staff has determined that the person with dementia is wandering the same time every day (8:00 am). After speaking with the family, staff learns that the person worked in a factory for 30 years and 8:00 am is when the individual left for work every day. With this information staff can build a plan to distract the person at this time with something work-themed (factory work). This would provide meaning and purpose to the person with dementia, which may curb the desire to wander. Not all TBPs work as planned and may need to be modified or changed until staff finds something that works.

New York

Part of training developed by Philip McCallion, PhD, at the State University of New York at Albany was adapted for care of people with intellectual disabilities and dementia. The training helps caregivers modify their perspectives regarding wandering by providing the following perspectives:

- Pacing and wandering behaviors in dementia are not all bad, and in fact most may be adaptive in that they provide exercise and physical stimulation.
- The aim of services is to accommodate these behaviors rather than limit them.
- The goal should be the provision of a safe level of wandering without putting people at risk of injury.
- Exit-seeking:
 - Residential life routinely provides two cues for exiting:
 - After each meal: the end of a meal can be a prompt to begin a new activity, including leaving the building
 - At shift change: staff putting on coats and leaving can be a prompt for the person to leave
 - Strategies to address these exiting cues include the following:
 - Purposeful activities for the person with dementia after each meal
 - Distracting activities at shift changes
- Self-stimulatory and restless pacers
 - Support opportunities for pacing and wandering by providing safe spaces (indoors and outdoors free of trip hazards and with discreet use of visual shields/distractions/barriers/silent alarms to reduce wandering beyond safe zones).

New York

The best way to address a potentially dangerous behavior is by preventing it from starting:

- *Understand the motivation:* Did someone walk 3 miles every day before the disease progressed? Is someone thinking it is time to go to work? Is there a visible garden outside and the person enjoyed landscaping? Is it “time” to get the kids off the bus/dinner on the table? This will help staff think of an appropriate personal prevention method.
- *Understand the environment:* Is a person in pain/too hot/too cold/hungry/needing to use the bathroom? Is the room too noisy or too dark? Wandering in these cases is a sign of unmet needs, which may be managed with some extra attention.

Sometimes wandering may be unavoidable. Possible strategies for coping include the following:

- *Activity stations:* Set up tables or carts along a path that can be a distraction to someone as he or she passes (a table with laundry, socks, and towels that someone might start folding; safe housekeeping supplies; simple crafting items like yarn or a block of wood with sandpaper; stuffed animals with a brush as a pet station; soft sports equipment; baby dolls with clothes). Interesting art work on the walls, aquariums, or flower arrangements with unusual colors or flowers can also serve as distractions.
- *Disguising certain doors to look like the wall:* Camouflage doors leading to unsafe places (like the kitchen or stairwells) by painting them similarly to the walls with trim and similar wallpaper, or use decorative murals to disguise doors as bookshelves). For some, Exit signs may be interpreted as literal instruction; a Stop sign also may be effective. Simple, easy-to-open fabric barriers attached with Velcro may also be enough to prevent someone from entering another resident's room or an activity room.
- *Clearly label important doors:* Help someone who is wandering because they want to use the bathroom but cannot find the right door, or who is trying to take a nap but cannot find his or her room. Shadowboxes or collages with personal items on the door to people's rooms could be reminders of where they live; actual photos (*not* clip art) of the toilet could be a reminder of the bathroom.

Utah

There are multiple methods to reduce wandering or exit-seeking with residents.

- *Black mats:* Black mats in front of exit doors are a way to deter individuals with dementia from using that particular door. For most people with dementia, the black mat is seen as a deep hole; as a result, they avoid that area. This also works when one resident tends to wander into another resident's room who does not want visitors. If the second resident does not have dementia, a black mat outside the second resident's room will often deter visitors. A black mat that extends the width of the doorway with a rubber backing and no pattern on the mat itself is recommended. If there is a double door involved, a larger mat may be needed.
- *Door masking:* Doors can be masked (i.e., made to blend into a wall or to look like something other than a door). With some creativity, paint, and talent, a door can be painted to look like the wall. However, because it might affect exiting the building in an emergency, not all relevant safety codes permit door masking. It is important to contact the local fire marshal to determine what is permitted.
- *Frosting of glass doors/windows:* Frosting the glass surface of doors is a way to reduce a person's ability to look out. If the doorway looks out into a parking lot, some people with dementia will want to leave when they see cars. The cars act as a trigger for the person who may think, "I need to drive somewhere" or "I need to get back home." Frosting glass surfaces may reduce exit-seeking. This can be accomplished by purchasing a spray can of glass frosting or by working with an artist to paint a frosted surface on the glass. Frosted contact paper is also available. As with masking doors, covering the windows in a door may not be acceptable to the fire marshals.
- *Window locks:* Many states will permit window locks so the window cannot be opened more than 6 inches.

- *Alarms:* Silent alarms can be used to alert staff if someone is opening a particular door or walking past a particular area in the building. An alarm-delayed exit door is another option, which means that when a person pushes on the door, an alarm will sound, and the door will open automatically within some period of time.
- *Staff training:* Sometimes exit-seeking increases during shift change in residences. Residents with dementia hear team members telling each other goodbye, see them put their coats on, and pick up on the cue that it is time to leave. An increase in noise because of staff greeting one another and socializing can cause confusion and an overwhelming environment for residents. By training staff to avoid highlighting the fact that they are leaving, leaving quietly by a side entrance rather than using the main entrance, keeping their belongings stored in an area that is not visible to the residents, and maintaining a calm environment for residents, the exit-seeking rush around shift change may be avoided.

Virginia

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 include the following:

- Why is the person trying to leave (intent)?
- Are there any environmental (e.g., noisy room) or internal triggers (e.g., need to go to the bathroom)?
- Which approaches work and which do not?
- Facility process and design factors may also affect wandering:
 - For residential communities and adult day centers, a scheduled day with activities provided every 2 hours along with hydration and a healthy snack can be helpful. Activities should be geared toward adults.
 - Additional staff so that activities can be provided on a regular basis would be appropriate.
 - An enclosed outdoor area that the person can go into alone (if the weather permits) and wander. A circular path in these areas may help to calm agitation. These areas should have benches and railings so that the person has something to help preserve balance.
 - There should be safe indoor wandering places in case of inclement weather.
 - Noise should be kept at a minimum and overhead pagers should be eliminated.
 - A quiet room should be available for agitated residents.
 - Carpet should be light in color with no design. Walls should be painted soft colors to give a calm feeling.
 - Clutter should be eliminated.
 - Remove attention from entries and exits by painting the doors the same color as the walls and putting rummaging drawers, artwork, and things to do on the other side of the room.
 - Use exercise and physical activity to reduce stress, tension, and boredom.
 - Provide cues: Use bright colors to draw residents into areas staff want them to be and pale colors in other areas. People tend to be drawn to bright areas.

- If way-finding is a problem, put directional arrows on the floor/walls toward bathrooms, use photos or pictures of a toilet to let people know where the bathroom is, put color-coded items on doors (i.e., yellow triangle, green ball) that can be associated with a person's room and can become familiar over time.
- Offer comfortable and quiet places to sit so people can have some quiet time away from the group.
- Assign volunteers to work one-on-one with people who need increased socialization.
- Help people feel comfortable with the environment so that they feel that they belong. Do this by creating a home-like setting with familiar items around them.
- Provide staff training on wandering, agitation, and anxiety, including identification of individuals who are a wander risk and how to respond to/prevent the triggers that lead them to wander.
- Post a sign at the door for family/visitors not to leave with anyone other than the person they came with or to alert staff when they are ready to leave so the exit can be monitored for individuals who are a wander risk
- Change door pass codes monthly.
- Use silent exit alarm systems for persons who tend to wander as part of a person-centered plan. For example a special ankle/wrist bracelet can alert staff when the individual who is a wander risk gets close to the door or tries to exit. Use closed-circuit TVs at exits, especially those that staff cannot easily observe.
- Use medical ID bracelets so emergency personnel know whom to call if they find the person.
- Have recent photos of people who wander and their information (i.e., physical descriptions) readily available to give to police and others should someone wander away. Update quarterly with a care plan. In addition, document each day what the person is wearing so that he or she is easier to find if he or she wanders away.
- A strong activity program is vital for residential communities, and adult day care.
- Develop a Wanderer Preparedness Committee to develop policies/procedures to follow in the event a person exits and to track and monitor individuals who are a wander risk.
- The first weeks in a new program/facility are the highest risk days for wandering because the environment is not familiar or comfortable. The routine, people, and atmosphere are unfamiliar. During this period, volunteers or staff can closely monitor and help the person feel comfortable in the new surroundings.
- Distract the individual who is a wander risk with something he or she enjoys (e.g., rocking in a rocking chair, reading, eating ice cream) as an alternative rather than negatively saying he or she needs to stop or not go outside.