# Advocating for Residents with Dementia:

# Common Scenarios

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# Dementia Defined: Progressive Dementia-Causing Diseases

### Dementia in the Nursing Home

Dementia is an umbrella term used to describe a group of symptoms affecting memory, thinking, and social abilities. Dementia is increasingly common in nursing homes. Currently, more than 50% of residents in nursing homes have some form of dementia and it is expected that that percentage will increase with time.

Despite the large population of people with dementia, many nursing homes and their staff are not prepared for the challenges of caring for those people. Many nursing homes shy away from individuals with dementia, citing concerns about liability and their ability to adequately care for the person. As the disease runs its course, residents who were once calm and easy-going may become more anxious. The role of the ombudsman is important in protecting these residents and advocating for their care.

### Alzheimer’s Disease (AD)

The most common form of dementia is Alzheimer’s disease, accounting for 60-80% of cases. Early symptoms include difficulty remembering recent conversations, names, or events, apathy and depression. Alzheimer’s leads to impaired communication, poor judgement, disorientation and confusion, behavior and personality changes, and difficulties speaking, swallowing, and walking.

Alzheimer’s causes abnormalities in the brain, including deposits of “plaques” and twisted protein “tangles”. It also causes nerve cell damage and death in the brain.

### Vascular Dementia (VaD)

Vascular dementia, once called multi-infarct and post-stroke dementia, is the second most common form of dementia. Approximately 20-30% of dementia cases are vascular dementia. Early symptoms include impaired judgement or ability to make decisions, plan, and organize. Other symptoms affect thinking and physical function, but they are specific to the location, number, and size of brain injury. Sudden changes may include confusion, disorientation, trouble speaking or understanding speech, and vision loss.

Vascular dementia is caused by infarcts (strokes) or bleeding in the brain. Diagnosis often includes brain imaging, which detects blood vessel problems.

### Dementia with Lewy Bodies (DLB)

Dementia with Lewy Bodies is the third most common cause of dementia, and is thought to account for 10-25% of dementia cases. Symptoms include changes in thinking and reasoning, confusion that varies significantly from one day to another or from one time of day to the next, visual hallucinations, delusions, trouble interpreting visual information, REM disorder, memory loss, and Parkinson’s symptoms.

Dementia with Lewy Bodies is frequently associated with Parkinson’s disease, but it is not always comorbid. DLB is diagnosed when symptoms develop before Parkinson’s disease symptoms or when dementia symptoms appear within one year of movement symptoms. Individuals are diagnosed with Parkinson’s disease dementia when they are originally diagnosed with Parkinson’s based on movement symptoms, and dementia symptoms appear a year or more later.

### Parkinson’s Disease Dementia (PDD)

Parkinson’s disease often results in a dementia similar to Alzheimer’s or Dementia with Lewy Bodies. As noted above, Parkinson’s disease dementia is diagnosed when dementia occurs after Parkinson’s disease has been diagnosed.

Parkinson’s disease dementia is caused by nerve cell damage caused by protein clumps in the brain.

### Frontotemporal Dementia (FTD)

Frontotemporal dementia, previously known as Pick’s disease, has many causes that lead to loss of function in certain brain regions. People with FTD generally develop symptoms at a younger age and survive for fewer years than people with Alzheimer’s disease. There are three types of FTD:

1. Behavior variant frontotemporal dementia (bvFTD) most prominently affects personality and conduct of people in their 50s and 60s, but it can develop as early as a person’s 20s or as late as their 80s. Brain damage most often occurs in areas that control conduct, judgement, empathy, and foresight.
2. Primary progressive aphasia (PPA) affects language skills, speaking, writing, and comprehension. PPA typically occurs midlife before 65, but it can occur later in life. There are two types of PPA:
   1. Semantic variant PPA – lose ability to understand or formulate words in a spoken sentence.
   2. Nonfluent/agrammatic PPA – speaking is hesitant, labored, or ungrammatical.
3. Disturbances of motor function dementias cause changes in muscle function with or without behavior or language problems. There are three types of motor function dementias:
   1. Amyotrophic lateral sclerosis (ALS) – also known as Lou Gehrig’s disease, ALS causes muscle weakness or wasting.
   2. Corticobasal syndrome – arms and legs become uncoordinated or stiff.
   3. Progressive supranuclear palsy (PSP) – muscle stiffness, difficulty walking, changes in posture, and affects eye movements.

### Creutzfeldt-Jakob Disease (CJD)

Creutzfeldt-Jakob disease is a rare prion disease, affecting approximately 1 in 1 million people annually worldwide. Symptoms include depression, agitation, rapidly worsening confusion and disorientation, problems with memory, thinking, planning, and judgement, difficulty walking, and muscle stiffness and twitches. There are three types of CJD:

1. Sporadic CJD – spontaneously occurring CJD typically appears between the ages of 60 and 85. It accounts for 85% of CJD cases and has no known cause.
2. Familial CJD – hereditary CJD caused by a dominant gene, meaning children of a parent who has familial CJD will also have familial CJD. Familial CJD accounts for 10-15% of cases.
3. Acquired CJD – caused by exposure to an external source of an abnormal prion. Approximately 1% of CJD is caused by exposure during a medical procedure or infected meats.

Creutzfeldt-Jakob disease is caused by proteins in the brain “misfolding” and causing brain damage.

### Normal Pressure Hydrocephalus (NPH)

Normal pressure hydrocephalus primarily affects people in their 60s and 70s. It is frequently overlooked because the symptoms are common in other brain disorders. NPH is caused by fluid buildup in the brain, sometimes caused by hemorrhages, infections, or inflammation. Symptoms include difficulty walking, memory loss, and incontinence. Sometimes, NPH can be corrected by draining the excess fluid.

*For resources for HD residents, call the HD Society of America at*

*(502) 637-4372.*

### Huntington’s Disease (HD)

Huntington’s disease is a genetic progressive disease in which symptoms develop between the ages of 30 and 50. People with Huntington’s disease typically survive about 15-25 years after the onset of their symptoms. Symptoms include uncontrolled bodily movement, declining thinking and reasoning skills, declining memory, concentration, judgement, and ability to plan and organize. People with HD may also experience depression, anxiety, uncharacteristic anger and irritability, and obsessive-compulsive behaviors.

### Wernicke-Korsakoff Syndrome (WKS)

Korsakoff syndrome is typically caused by Wernicke encephalopathy. Wernicke encephalopathy is a brain reaction to a severe lack of thiamine, which helps the brain produce energy. Symptoms of Wernicke encephalopathy include confusion, staggering, lack of coordination, and abnormal eye movements. While alcohol abuse is commonly associated with Korsakoff syndrome, it can also be caused by AIDS, chronic infections, and poor nutrition. Symptoms of Korsakoff syndrome include trouble learning new information, inability to remember recent events, long-term memory loss, and false ideas.

# **Communicating with Residents with Dementia**

### Words Matter

When working with a resident with dementia, words matter. Many nursing homes, medical professionals, families, and even ombudsmen use words in our daily work that are derogatory and discriminatory against people with dementia. As society evolves and we learn more, we must change our vocabulary. The disability community coined the phrase “nothing about us without us” to fight to be included in discussions, research, and policymaking. The phrase can easily be applied to dementia care, research, policy, and advocacy.

“How you relate to us has a big impact on the course of the disease. You can restore our personhood and give us a sense of being needed and valued… Give us reassurances, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain our social networks.”

Christine Bryden

Words are powerful. The use of appropriate words can dramatically help to reshape attitudes, actions, and thoughts about people who are living with dementia. Our words should be supportive, respectful, and life-affirming. Refer to this chart for the best way to communicate with residents with dementia:

|  |  |  |
| --- | --- | --- |
| Recommended Words: | Words to Avoid: | Rationale: |
| Person living with dementia  Resident with dementia  Resident  *Dementia does not victimize a person – poor care, abuse, and disrespect victimizes a person.* | Patient  Sufferer  Victim  Demented  Demented person  Dementing illness  Senile  Afflicted  Wanderer  Sundowner  Feeder  Empty shell  Losing his/her mind  Loss of self  Not all there  Behavior problem  PWD | Words listed to avoid are considered derogatory and offensive and should not be used.  The use of acronyms in research work infers a lack of sensitivity and respect for the personhood of an individual or group of people. Use words as a sign of respect. |

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| --- | --- | --- |
| Recommended Words: | Words to Avoid: | Rationale: |
| Dementia | Alzheimer’s (unless used to refer specifically to that type of dementia) | Not everyone who has dementia has Alzheimer’s disease. It is insensitive and confusing to refer to all dementias as Alzheimer’s. The term “dementia” is inclusive and appropriate to use as a general term. |
| Care partner  Spouse, wife, husband, daughter, son, family member, loved one, friend  Carer | Caretaker  Caregiver  Custodian  Dutiful wife/husband  Person burdened by care | It is important to use words that recognize the reciprocity and caring relationship between the person with dementia and their care partner. While the level of support varies based on the stage of the condition, words should support a positive relationship-based connection. |
| Providing support  Providing Assistance  Providing Care & Support | Providing caregiving  Providing care | Words such as “caregiving” and “care” infer a one-way relationship. |
| Expressions of unmet need  Behavior expressions  Behaviors expressed by a person living with dementia | Behavior problem  Challenging behavior  Difficult behaviors  Behavioral and psychological symptoms of dementia  Vocalizer  Aggressor | Behavioral expressions are expressions of an unmet need, such as pain, hunger, thirst, boredom, loneliness, or an underlying medical condition. Understanding behaviors from this broader perspective aids in uncovering the root cause of the behavior being expressed. |

*When you are with the resident, talk* ***to*** *them, not about them. Give the resident the chance to speak for himself.*

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| --- | --- | --- |
| Recommended Words: | Words to Avoid: | Rationale: |
| Individualized practices  Personalized Practices | Non-pharmacological interventions  Treatment  Intervention | “Non-pharmacological interventions” infers a medical focus rather than a holistic one, which is what our nursing homes should be focused on. Additionally, the term “individualized practice” reinforces a focus on the person rather than generic practice. |
| The condition is:  Challenging  Stressful  Life-changing  The condition feels:  Hopeless  Depressed | The condition is not:  Hopeless  Tragic  The long goodbye  Fading away  Burdensome | People with dementia are alive – they can feel, laugh, and cry no matter what stage they are in. There are so many things that residents with dementia can continue to do during the course of the condition. |
| Young onset dementia | Early onset dementia | “Early onset” is sometimes used to describe dementia symptoms that occur before age 65 but it is also used to describe the first cognitive impairment symptoms experienced at any age. To avoid the term, “young onset” is seen as preferable. |

*“I often forget where things are too…” and “I can’t find my words either… we’re just getting older” can feel invalidating to a resident with dementia, like they are just over-exaggerating normal aging. Instead, find other opportunities to connect over shared interests.*

### Repetition

A person with dementia may do or say something over and over again, like repeating a word, question, or activity. The person may pace or undo something that has just been done. In most cases, he or she is looking for comfort, security, and familiarity. It is rarely harmful, but it can be stressful for the care partner or other residents.

How can we advocate for a resident who repeats words or actions?

* Ask if the facility has looked for a reason for the repetition.
  + Staff should try to find out if there is a specific cause or trigger for the repetitive behavior. Triggers may be visual or auditory, they may include feelings of hunger, thirst, or pain, or they may be triggered by a lack of social interaction or inappropriate care strategies by staff.

*Care Planning Point:*

*Remember to encourage all residents to attend their care plan meeting. Their presence reminds us and staff to keep the focus on their care.*

* Remind staff to focus on the emotion.
  + Rather than reacting to what the person is doing or saying, staff should respond to how she or he is feeling. Does this happen at a certain time of day or during conversations about a certain topic?
* Can staff turn the action or behavior into an activity?
  + If the resident is rubbing his hand across the table, staff might ask if he would like to help them dust.
* Remind staff to stay calm and be patient.
  + Staff should reassure the resident with a calm voice and gentle touch. Relaxed physical contact like hand holding can be comforting.
* Ask staff to provide an answer.
  + Staff should answer repetitive questions in a calm and patient tone. It may help to write it down and post it in the resident’s room.
* Advocate that the staff engage the person in an activity.
  + The resident may simply be bored and need a distraction.

### Yelling

Poorly managed pain can result in behavioral symptoms and lead to the unnecessary use of psychotropic medications. Residents who yell and moan are giving clues to their needs. When working with a resident who moans or yells, it is important to find out whether they have had a recent pain assessment.

Pain assessment should occur routinely, especially when residents have conditions likely to result in pain or if the resident indicates in any manner that they have pain. For residents who cannot verbally communicate, direct observation by staff can help identify pain and pain behaviors. Signs of pain included labored breathing, grimacing, rigid posture and clenched fists, and loud moaning, groaning, or crying.



### Music & Art

Music and art can enrich the lives of people with dementia. They create an opportunity for self-expression and engagement, even after dementia has progressed. Studies have found that music may reduce agitation and improve behaviors.

When advocating for a resident to experience music as an activity, it is important that the facility finds music that is familiar and enjoyable to the resident. The facility should ask the resident or his or her family about preferred genres or artists. Matching music to mood is important – tranquil music could be used to create a calm environment for a resident who is experiencing anxiety or behaviors while a faster tempo can energize a resident. Remind facilities to avoid sensory overload by eliminating other noises.

Activity departments often plan art projects for residents. As ombudsmen, we can advocate for adult-level projects instead of childlike projects. Remind facilities that some residents may need help beginning, such as starting the brush movement and then letting the resident take over. Some projects may take a while, and could be stretched over a couple of days.

### Interviewing Residents with Dementia

Ombudsmen frequently work with residents with dementia. When interviewing these residents, special considerations may be necessary.

* Find a calm environment for your interview. Consider finding an empty conference room or quiet day room.
* Eliminate distractions and competing noise.
* Reintroduce yourself and your role. Avoid asking a resident if they remember you.

*Care Planning Point:*

*Model good interviewing for facility staff. In care plan meetings, ask the resident what they want and wait for their response.*

* Be sure to capture the resident’s attention before starting your interview. Speak only when the resident’s attention is directed toward you.
* Sit and speak face to face. Do not speak directly into a resident’s ear – they won’t be able to read your lips or facial expression.
* Speak clearly and on an adult level. Don’t yell – it makes it harder to read your lips and facial expression.
* Give concise questions or directions. Only ask one question at a time.
* Repeat information as necessary, but be sure to allow her time to hear your question, interpret your words, formulate a response, and verbalize her answer.

# Working with Residents with Behaviors

Behaviors are common symptoms in residents with dementia – research has found that more than 50% of nursing home residents have behaviors. Common behaviors experienced by residents with dementia include wandering, yelling and screaming, physical or sexual aggression, resistance to care, and agitation.

*Care Planning Point:*

*If the facility reports they have tried to identify a pattern and found nothing, probe further. Who observed the resident? What notes were made? What was the observer watching for, and what tool did they use to record their findings?*

Behaviors are not problems, they are communications. Behaviors may be related to physical pain, discomfort, overstimulation, unfamiliar surroundings, complicated tasks, or frustrating interactions. It is the provider’s job to find the cause of the behaviors. Many times, however, facility staff try to manage behaviors without searching for a root cause.

Once you have obtained a resident’s (or resident representative’s) consent to investigate, consider the following tips.

### Identifying Behaviors

When speaking with facility staff who are considering discharging a resident with behaviors, investigate further by asking the following questions:

* What is the behavior?
* Is it harmful? To whom?
* Has the facility monitored the behavior to find a cause? What triggers the behavior – environment, time, a particular person?
  + Other triggers could include vision and hearing impairments, hunger, thirst, pain, lack of social interaction, or inappropriate strategies for care by staff.

Once you have found out what the behavior is, find out what the facility has done to address the behaviors.

* Has the facility assessed the resident’s pain?
* Has the facility reviewed the resident’s medication? Does the resident need to be assessed?

*Care Planning Point:*

*Has the facility discussed the behavior with their psychiatric or behavioral consultant?*

* Are the person’s needs being met? Consider needs beyond food, water, and medication. Consider psychosocial needs.
* Has the facility adapted the environment for the resident?
* Has the staff tried changing their approach or reaction?
  + A change in approach or care plan must be applied **consistently** and evaluated regularly.

If the facility has tried the above, have they explored other solutions? The answer may not be easy, and the solution for one resident may not work for another. It is important that ombudsmen continue to advocate for the resident to get care for their behaviors.

*An 83 year old man repeatedly entered the rooms of other residents, removing magazines and papers from their nightstands and trays. After meeting with the family, the staff found he had been a letter carrier for 40 years. The facility found the man a canvas shoulder bag and brought old magazines and empty envelopes to place in the common areas. He quickly became preoccupied with collecting the planted materials and tended to stay out of other residents’ rooms.*

This facility identified the behavior, recognized it as low harm, investigated his personal history, and found an appropriate, individualized solution. This environmental adaptation must be consistent to ensure he continues to stay out of other residents’ rooms.

### Resident to Resident Aggression

Resident to resident aggression (RRA) is a negative and aggressive physical, sexual, or verbal interaction between long-term care residents that is considered unwelcome. RRA has a high potential to cause physical or psychological distress in the person being mistreated.

Examples of resident to resident aggression include:

* Biting
* Bullying
* Destroying property
* Grabbing
* Hitting
* Inappropriate touching
* Kicking
* Physical sexual advances
* Pushing
* Racial/ethnic slurs
* Scratching
* Screaming
* Sexual harassment
* Spitting
* Taking personal items
* Threatening
* Throwing things

Resident to resident aggression common in nursing homes, but it is preventable. It is important to know who is at risk of RRA.

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| --- | --- |
| Risk Factors | |
| Resident Characteristics | **Facility Characteristics** |
| Residents with significant cognitive impairments, such as dementia and mental illness | Inadequate number of staff |
| Residents with behavioral symptoms related to dementia or other cognitive impairment that may be disruptive to others (yelling, repetitive behaviors, calling for help, wandering into others’ rooms) | Lack of staff training about individualized care in order to support residents’ needs, capabilities, and rights (e.g., resident-centered care, abuse prevention, care for those with limited capacity, dementia, and mental health needs) |
| Residents with a history of aggressive behavior and/or negative interactions with others | Lack of meaningful activities & engagement |
|  | Crowded common areas (too many residents in one room, equipment/obstacles in common areas) |
|  | Excessive noise |

Residents who are identified as aggressive should not be isolated or punished. People are social beings who require human interaction and positive regard. Studies have found that residents are often labeled as non-compliant after just one incident of not doing as instructed. Consequently, after a resident is labeled “non-compliant,” facility staff stop inviting the resident to activities or providing compassionate care. If loneliness is a trigger for behaviors, this isolation serves only to further ostracize a resident with behaviors.

*Care Planning Point*

*When investigating a complaint of RRA, a facility may place a resident on 1-on-1 or 15 minute checks for 24 hours. A care plan meeting may be necessary to address triggers or causes of the RRA. Ask what the facility intends to do after that 24 hour period to ensure resident safety every day.*

Instead of isolating a resident experiencing behaviors, advocate that the facility staff reach out and communicate with that resident. Using the previous suggestions for identifying the behavior, find the root cause of the residents’ aggression.

Residents and facilities identified as high risk should consider the following recommendations to prevent and reduce RRA:

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| Recommendations to Prevent & Reduce Incidents of RRA | |
| Environmental Considerations | **Care Practices** |
| Clear common areas of clutter | Develop comprehensive care plans which provide individualized, resident-centered care. Implement best practices for supporting residents with behaviors. |
| Reduce noise and overcrowding | Train facility staff on person-centered care, dementia, and mental illness. Develop policies regarding how to prevent, recognize, respond, report, and document RRA. |
| Provide areas for supervised, unrestricted, safe movement. | Identify residents with risk factors for RRA and develop care plans to meet their needs. Monitor their care closely. |
| Identify environmental influences on behavior and adjust accordingly (temperature, lighting). | Identify root causes of behavior symptoms and reduce or eliminate those causes (pain, boredom, loneliness) |
| Promote meaningful activities and opportunities for engagement for all residents based on individual needs, interests, and abilities. | Implement consistent staffing assignments so residents and staff are more comfortable with each other and staff are more familiar with resident needs and changes in behavior. |
|  | Ensure adequate staffing levels in order to meet resident needs and provide supervision. |

Remember to advocate for both residents involved. All residents should feel safe in their home, and residents experiencing behaviors should receive the care they need. Facilities may need to be reminded of their requirement to document, investigate, and report the incident.

### Involuntary Transfer or Discharge

Residents who experience behaviors are often at risk of involuntary transfer or discharge. We know that there are only 6 reasons a resident can be discharged and “behaviors” is not one of those reasons. Many nursing homes, then, will frame the issue as though they cannot meet the resident’s needs or the resident is endangering other residents. However, the facility must do more than just demand the resident leave.

When a facility decides to involuntarily discharge a resident for behaviors, they must provide a written notice at least 30 days before the proposed date of eviction. The notice must tell the resident or their representative:

1. The reason for discharge
2. The date of proposed discharge
3. The location to which the resident is to be moved
4. The resident’s right to appeal
5. The SLTCO name, address, and telephone number

If the notice is missing any piece of the above information or if it is incorrect, the notice is deficient.

Ombudsmen who work with residents and families who have received a notice of discharge should make a referral to their legal aid service provider and begin investigating the discharge. Ask the facilities the questions outlined on page 11 to find out why the facility has issued the discharge. Ombudsmen may also ask to view documentation of the behaviors. How has the facility documented these incidents?

Consider the location to which the resident is being discharged. Is it a family member’s home? If a nursing home cannot meet a resident’s needs, is it reasonable to expect a family member to be able to provide 24 hour nursing care? Is it another nursing home? What about the other nursing home makes them more qualified to care for the resident? The resident is in the nursing home for the very reasons that cause behaviors, so discharging them to a private home or other nursing home will not address the root cause of the behaviors.

# Anxiety & Agitation

Residents with dementia may experience anxiety and agitation in the nursing home. When working with a resident who is agitated, consider possible causes and coping strategies.

*Care Planning Point*

*Ask questions in the care plan meeting about what triggers have been identified and how they can be managed. Residents who experience anxiety during care activities should be accommodated to avoid further anxiety or agitation.*

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| Possible Causes | Investigate Further |
| The environment is too stimulating. | Can the facility simplify the environment? |
| The resident is experiencing pain. | Ask the facility how they evaluate the resident for pain. Can the resident communicate their pain? |
| There is a change of routine or care partner. | Advocate that the facility maintain a consistent routine and consider consistent staffing assignments. |
| The care partner is agitated. | Care partners should us a positive, matter of fact, calm approach. Does the facility need the ombudsman to provide an in service on residents’ rights and elder abuse? |
| The resident is experiencing too many demands. | Advocate that care partners simplify their instructions and avoid questions that require memory. |
| The resident is bored. | Ask the facility what activities they plan for residents with dementia. Advocate for the resident to be included in activities that he or she is interested in. |
| The resident’s dementia causes misinterpretation. | The care partner should not argue with the resident’s reality, but reassure the resident that they are safe. |
| The resident is experiencing side effects from medications. | Advocate that the facility order an evaluation of the resident’s medications. |

### Bathing Without a Battle

Ombudsmen frequently work with residents and families who are dissatisfied with the bathing routine at their nursing home. For residents with dementia, bathing can be extremely confusing, frightening, and traumatic. Bathing is necessary to prevent skin breakdown and infection, but residents always have the right to refuse care. Rather than using a resident’s refusal as an opportunity to avoid care, there are many ways facilities can decrease anxiety for residents who refuse or fight bathing care.

It is important to know why bathing is stressful for a resident. It is not enough just to say “the resident resists care during bath time.” The facility must explore why the resident resists care.

Once the facility has identified the cause of a resident’s anxiety, they should work to find a solution. As ombudsmen, our role is not to tell the facility how to fix a problem. We can, however, share solutions gleaned from other facilities experiencing similar situations.

*Ms. Allen had aphasia and became agitated during her morning hygiene routine. She shouted the same word over and over again, becoming more distressed as the aides worked. The facility staff rotated often, so Ms. Allen rarely had the same aide twice. Ms. Allen’s daughter sought the help of the ombudsmen, who advocated for consistent staff for Ms. Allen’s morning routine. The facility decided that Ms. Allen’s favorite nurse aide would give her bath. A few days after, Ms. Allen’s daughter called the ombudsman to report her mother’s bathing routine was going well! The aide realized that Ms. Allen was asking for something when she repeated that word. After the aide gave Ms. Allen her glasses, she quieted and even began participating in her care!*

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| --- | --- |
| Cause of Anxiety | Possible Solution |
| The resident is cold and uncomfortable. | Keep the room and water temperatures comfortable. Suggest the facility install an extra heater in the bathroom to keep the air as warm as the water.  Suggest modifying the shower chair to be cushioned and more comfortable. |
| The resident is uneasy being so exposed. | Undress the person in the bathroom. As the resident is undressed, cover them with a bath blanket. |
| The resident is overwhelmed and confused, or afraid of bath time. | Advocate for the facility to use consistent staffing so that residents are familiar with their care partner. Employing a “bath” nurse aide means residents do not know who is undressing and touching them during their bath time.  Ask the care partner to fill the tub before bringing the resident into the bathroom. The room will be warmer and considerably quieter.  Suggest that care partners avoid background noises and conversations and instead speak calmly and positively to the resident, using reassuring phrases.  Advocate for the resident to participate in their bath – the care partner can give them a washcloth or put their hand over the resident’s to remind them of what they are doing.  Ask care partners to stay focused on one part at a time – if two aides are providing care, they should not each wash a body part at once.  Advocate that the facility use a sock or pillowcase over the showerhead to decrease the force of the spray.  Suggest the facility decorate the bathroom in a homelike fashion, not a sterile room. Music and aromatherapy oils can be soothing.  Ask the facility to show the resident the bathroom when they are not going to the bath to help them become acquainted. |
| The resident feels like they have no control over their care. | Suggest to the facility that they ask residents what time they would like to have a bath, and whether they would like a tub bath, shower, or bed bath. If the resident cannot answer, the facility may ask family or observe the resident’s preferences. |

### False Ideas

Dementia may cause a resident to become confused about where they are or what day or year it is. We also know that some forms of dementia cause hallucinations and/or delusions. When visiting with a resident who is experiencing these false ideas, it is important to be understanding and reassuring.

*Care Planning Point:*

*If a resident is experiencing false ideas, ask in the care plan meeting what the facility has done to identify triggers. Before using medication, the facility should attempt non-drug treatments.*

If a resident is worried about her father being late coming home but we know her father passed away years ago, do not correct her and remind her that her father has died. Reassure her and try to redirect her attention. Correcting a resident’s false ideas can be traumatic and embarrassing.

If a resident has reported to you that there is a monkey living in her ceiling, or his daughter has stolen his fortune, or there are scary men who roam the hallways late at night, it is important to reassure the resident and try to understand their reality. Let the resident know you care without trying to argue or convince them they are wrong. It is important that residents who experience extremely troubling delusions or hallucinations receive proper medical treatment. Treatment should start with non-drug approaches, but could require medication.

# Residents Who Wander

Residents with dementia often wander – some estimates suggest more than half of people with dementia wander at some point. While residents who wander often look as though they are walking aimlessly, wandering is very often a response to an unmet need. Residents who wander may be looking for human contact or the toilet, or they may be experiencing hunger, thirst, noise, or pain. Sometimes, residents wander as an attempt to follow an old routine, such as going to work or picking up their children.

Wandering is often also referred to as exit-seeking because many residents appear to be trying to leave the nursing home. While most residents who wander are not actively trying to leave the facility, they may experience harm as a result of their wandering. Residents who wander may become locked out of the nursing home while searching for a bathroom. They may wander into another resident’s room and be yelled at or pushed out. Addressing a resident’s wandering can be challenging, but nursing homes must ensure the safety of residents who wander and the privacy of residents who find wandering residents in their rooms.

Like many of the other scenarios described thus far, it is important to identify the “why” of wandering. By using person centered care, facilities can work with a resident’s family and loved ones to try to find a reason for wandering. By documenting the frequency, timing, and triggers for wandering, the facility can create a plan of care that prevents the resident from wandering dangerously.

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| --- |
| Preventing Wandering |
| Clearly label important doors: Help residents with dementia find the bathroom by clearly labeling the restroom door with words and pictures. Help residents find their rooms with pictures and personal items in a frame or shadowbox outside their door. |
| Disguise “wrong” doors: Camouflaging the door to the kitchen or stairwell can help residents avoid entering unsafe locations. The door could be made to look like a wall or bookshelf. Exit doors may also be disguised, but facilities should check with fire marshals to determine what is permitted. |
| Provide “activity stations”: Tables with activity items may distract a resident from exit-seeking. The table could have laundry, cleaning cloths, simple craft items, or other items. |
| Black mats in doorways: Black mats in front of exit doors can be a way to deter residents with dementia. Most people with dementia interpret the mat as a deep hole and avoid the area. Facilities could also put mats in front of other resident’s doors, as long as the residents occupying the room agree. |
| Alarms: Silent alarms can be used to alert staff when a particular door is open without causing stress to residents. Alarm-delayed exit doors are another option, which alarm when someone pushes on the door and open after it is pushed for some time. |
| Staff training: All staff should know how to redirect a resident who has wandered into an inappropriate location. |

### Safe Wandering

Wandering cannot usually be resolved by stopping the behavior. It is important that facilities take these steps to create a safe environment for residents who wander instead of using medication that causes residents to become lethargic or sleepy. Safe wandering can be achieved through the suggestions above or through the creation of safe wandering areas. An enclosed outdoor courtyard can be an option, and hallways can be better designed to keep residents who wander safe.

*Every day, Ms. Price would leave her room and enter Ms. Jonas’ room without knocking, walk to the window, and sit in a chair. She refused to move when Ms. Jonas confronted her. Staff could not think of a reason Ms. Price would leave her own window to go sit at Ms. Jonas’, so they called Ms. Price’s out-of-town son. The social worker asked how Ms. Price used to spend her days. The facility learned that Ms. Price was an avid gardener. After learning about her interest in gardening, staff realized that her window faced the parking lot while Ms. Jonas’ faced a garden. As soon as a room was available, Ms. Price was moved to a garden-view room. In the meantime, staff brought Ms. Price’s chair to a common area window so she could enjoy the flowers comfortably.*

### Residents Who Want to Go Home

Ombudsmen frequently encounter residents who ask for help going home. Oftentimes, for residents with dementia, the desire is an indication that the resident is not comfortable in the nursing home. The request is for a feeling of home, not always a specific desire to be back in the house they once lived. For these residents, an ombudsman can work with family to identify routines and personal items that can be brought back into their lives in the nursing home.

*Mrs. Johnson had been in the nursing home for just a few months and was having difficulty adjusting. Her daughter had placed her in the local nursing home after Mrs. Johnson stopped cooking and cleaning and taking her medications. She visited often, and every time she was with her mother she asked her to take her home. Mrs. Johnson’s daughter couldn’t care for her at home, but after months of being asked she decided to take her mother home for dinner one night. After preparing Mrs. Johnson for an evening out, she drove her back to her home. The car pulled into the driveway and Mrs. Johnson asked her daughter, “Where are we?” When asking to go home, Mrs. Johnson was actually expressing her need for more comfort and familiarity.*

# Restraints

### Physical Restraints

Physical restraints are objects used to prevent a resident from moving. Physical restraints have been found to be dangerous and unhealthy, and many nursing homes no longer use physical restraints. The use of physical restraints is unlawful when used for the convenience of staff, because of short staffing, as a punishment, or in the place of a thorough assessment and care planning.

### Chemical Restraints

Chemical restraints are psychoactive drugs used to treat behaviors in place of personalized care and sufficient staffing. Chemical restraints are dangerous and unhealthy, but they are still used at higher levels than physical restraints. It is important when working with residents with dementia that the ombudsman advocates for non-drug treatment to avoid the side effects and risks of chemical restraints.

*Care Planning Point:*

*Before a resident is prescribed a psychoactive drug, find out what non-drug treatments they have tried. Have they truly identified the cause of the behavior, or is the drug going to mask a resident’s pain or needs?*

Risks of chemical restraints include:

* Increased chance of falling
* Loss of continence
* Pressure sores
* Infections
* Constipation
* Repetitive movements (tardive dyskinesia)
* Stiff posture or the inability to sit or stand straight
* Hallucinations
* Blurred vision
* Masking the true cause of a behavior
* Death

It is unlawful for nursing homes to use chemical restraints except to treat medical symptoms diagnosed by a physician. Similar to physical restraints, chemical restraints are unlawful when used for the convenience of staff, because of short staffing, as a punishment, or in the place of a thorough assessment and care planning.

*Mr. Saxon was admitted to the nursing home on a number of medications, one of which was a sleeping medication. He had been prescribed the medication with his wife died years ago. Mr. Saxon was sure the medication was the only way he could sleep, but staff knew that sleeping medications can be unsafe. The staff worked with Mr. Saxon to try to reduce the dosage slowly and carefully while implementing individualized care practices. Mr. Saxon took his bath at night and eliminated caffeine in the afternoon and evening. He participated in activities during the day and relaxed in the evening. Over the next few months, Mr. Saxon was able to reduce his dosage and eventually come off of the sleeping medication.*

Ombudsmen and facility staff can follow the “IDEAA” strategy to address wandering and other behaviors.

**Id**entifying the challenging behavior

* What is the challenging behavior?
* Is the behavior harmful?

**E**ducating care partners

* Understand the cause of the behavior (wandering)
  + Health: Is the person taking new medications, getting sick, or in pain?
  + Environment: Is it too noisy, hot, or cold? Is the resident unfamiliar with the environment?
  + Task: Is the task too difficult for the resident? Are there too many steps? Is it something new?
  + Communication: Is it hard for the resident to speak or understand?
* Understand the meaning of the behavior of the person
  + Does the person feel as though they are being treated like a child?
  + Are there things that remind the person of unhappy experiences? (music, tasks, people)
  + Does the person feel a sense of insecurity, discomfort, or boredom?

**A**dapt

* Try different things. Pay attention to the person’s feelings. Practice being calm, gentle, and reassuring.
* Distract or redirect by:
  + Offer the resident something he or she likes to eat
  + Turning on the TV or radio
  + Ask the resident for help with an activity
  + Lead the person to a different room

**A**ddress the cause or triggers of the behavior

* Keep tasks and activities simple
* Keep the environment as calm and quiet as possible
* Speak slowly and clearly and try not to say too much at one time
* Don’t argue with the resident
* Find meaningful, simple activities so the resident is not bored