NURSING HOME
STRATEGIES TO ENHANCE QUALITY OF LIFE FOR RESIDENTS WITH DEMENTIA

STATE OF WISCONSIN
DEPARTMENT OF HEALTH SERVICES

Division of Quality Assurance
Bureau of Education Services and Technology

P-01040 (05/2015)

Note: *The approaches identified in this document are not mandatory. They are proven approaches that may be useful in helping your facility sustain compliance.*

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BACKGROUND INFORMATION

The Division of Quality Assurance periodically publishes a list of the 10 most frequently cited federal health requirements in nursing homes. A review of these citations was conducted to determine if consistent themes appeared related to caring for residents diagnosed with Alzheimer's disease or other dementia.

The review identified three recurring themes of serious violations – elopement, challenging behaviors (combativeness, resident-to-resident abuse, resistance to cares, etc.), and sexual behavior.

As a result of this study and to promote and foster a greater understanding of the needs of people with Alzheimer's disease or other dementia, the following document was created to provide guidance on approaches to reduce or prevent challenging behavior from occurring.

The following chart shows Wisconsin's 10 most frequently cited federal health requirements in 2014:

10 Most Frequently Cited Federal Health Requirements in 2014		
Rank	**Tag**	**Description of Regulation**
1	F441	Infection control program designed to prevent the development and transmission of disease and control the spread of infection
2	F323	Facility is free of hazardous environment/supervision and assistive devices to prevent accidents
3	F314	Services and treatment to prevent and/or heal pressure ulcers
4	F371	Food stored, prepared, distributed, and served in a manner that prevents foodborne illness
5	F329	Each resident's drug regimen is free of unnecessary drugs
6	F225	Report and investigate allegations of abuse, mistreatment, neglect and misappropriation
7	F309	Care and services to attain/maintain highest practicable level of well-being
8	F315	Care and services to restore as much normal bladder function as possible
9	F282	Services provided by qualified personnel in accordance with the plan of care
10	F280	Periodically review and revise the care plan

ELOPEMENT

The following are examples of serious violations involving elopement, challenging behaviors, and sexual behavior that resulted in significant harm for residents. The examples include approaches that may have prevented the serious consequences experienced by the residents. Each section also includes a list of additional resources a provider may access for more information.

Examples

- *An 82-year-old resident with diagnoses that included anxiety, depression, and dementia with behaviors cut off the Code Alert bracelet at least 12 times and set off a door alarm twice. Resident's behavior changed significantly as s/he became increasingly angry and expressed a desire to leave the facility. Certified nursing assistant was one-on-one with the resident but left to assist another resident. The police located the resident outside, about 2½ hours later. The police noted that the resident was cool to the touch. The low temperature that evening was 43 degrees, and staff stated it was a "super dark night."*

- *A resident with dementia did not receive adequate supervision and exited the two alarmed doors at the end of the living unit. After the alarm sounded, staff did not check the immediate area or the stairwell and did not do a "head check." Resident was outside for over 12 hours, wearing a hospital gown and gripper socks. The resident was hospitalized and noted to be hypothermic.*

Problem

Residents with dementia eloping from long-term care facilities may be at high risk of harm due to hazards they encounter.

Goal

To prevent resident elopements and maintain resident safety.

Approaches

1. Conduct a thorough assessment of all individuals prior to admission to the facility. The assessment should include important components such as confusion and other symptoms of cognitive impairment that could cause exit-seeking behavior. Determine if the individual has a history of exit-seeking behavior. Ensure that the facility has the capacity and capability to provide the appropriate services to meet the needs of the individual at risk for elopement.

2. Complete a thorough risk assessment for each resident. Questions to ask team members should include:
   - Does resident make statements questioning the need to be here or about wanting to go home?
   - Does resident open doors to the outside for no reason?
   - Is resident displaying behavior, body language, etc., indicating an elopement may be forthcoming?
   - Has resident packed belongings to go home, or does resident stay near an exit door?

3. Determine if family members or others have used successful strategies to prevent unsafe wandering or successful exiting.

4. Create a secure outdoor environment free of obstructions with adequate lighting and low glare. Ensure that transitions from even to uneven surfaces (e.g., grass to sidewalk) and that other areas are smooth.

5. Provide easy, safe, and secure access to the outdoors while maintaining control over unauthorized exiting, and accompany resident at risk of elopement when outdoors.

6. Keep items that one picks up before leaving the house (e.g., car keys, umbrella, coat) out of sight, as they may trigger wandering behavior.

7. Develop a preventative action plan for residents at risk for elopement. Important elements of your plan would include:
    - A plan to ensure that all facility staff is able to recognize residents at risk and be prepared to intervene.
    - Identify, in the care plan, each resident's supervision needs and approaches to meet the needs, and develop a staffing schedule that will enable staff to observe the location of each resident at risk for elopement at all times.
    - Determine and document the triggers that may cause exit-seeking behavior (e.g., time of day, thirst, hunger, activity, pain, staff interaction, change in bowel habits, fear) for each resident at risk for elopement.
    - Maintain current photographs of residents at risk for elopement, and keep the photographs in a central location.
    - Maintain any alarm system that the facility utilizes to alert staff of a possible elopement; develop a schedule for monitoring the alarm system to ensure that it is operating correctly, and monitor staff response to a door alarm.
    - Develop a written emergency plan that directs staff on how to respond to a resident elopement; the plan should include how the search for the resident is to be conducted, both on and off the facility grounds, and the procedure should provide specific times the police or family members should be notified.
    - Communicate to staff the risks for elopement, location of resident photographs, supervision needs, how to ensure the alarm system is working, and the importance of quickly responding to a resident elopement.
    - Keep resident assessments and care plans current and up to date.

8. Evaluate the "who, what, where, and how" of an elopement incident. Determine what interventions should be added or changed to prevent any future elopements. Update the resident's care plan to include the interventions, and communicate the interventions to staff.

9. Assess any change in condition related to exit-seeking behavior on a routine basis.

Elopement Resources

- Creating Effective Systems to Manage Wandering Behavior, *Guidance for Long Term Care Facilities in New York State*, May 2005
  https://www.nccdp.org/WanderingBehavior5-10-05Final.pdf
- DQA Memo 10-009, Elopement Guidelines for Assisted Living Facilities
  https://www.dhs.wisconsin.gov/dqa/memos/10-009.pdf
- Alzheimer's Association Campaign for Quality Residential Care
  http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf
- Elopement Risk Assessment
  http://www.whca.org/files/2013/04/elopment_risk_assessment.doc
- Arkansas Innovative Performance Program: Elopement and Wandering Assessment
  www.afmc.org/aipp
- UCLA Alzheimer's and Dementia Care Program: Wandering
  http://dementia.uclahealth.org/body.cfm?id=69

CHALLENGING BEHAVIORS

Examples

- *Resident admitted to the facility with diagnoses including dementia related to Alzheimer's disease and Parkinson's disease. This resident has shown aggressive behaviors to residents and staff multiple times. A certified nursing assistant (CNA), who witnessed an incident, wrote the statement, "Was standing at desk when I saw resident come up to another resident full force and punch [him/her] in the ear." The facility's investigation report contains a statement, written by an activity aide, which states, "Resident took another resident's gait belt…had an angry look on [his/her] face and towered over me with the gait belt raised up and hit the other resident with gait belt on [his/her] right arm." The aggressive resident remained in the facility after this incident. The facility did not provide appropriate supervision or services to the aggressive resident in order to ensure the protection of other residents.*

- *Resident admitted to facility with diagnoses to include dementia with behavioral disturbance, Alzheimer's, depressive disorder, and anxiety. Resident noted to have poor impulse control, anger, depression, and history of harm to others. Staff states resident paces the halls and makes angry-like facial grimaces and growling-like noises through clenched teeth; noted to become angry when told not to go into other residents' rooms. The resident was unsupervised, wandered into another resident's room, sat on her, and woke her up. Resident also wandered into another resident's bathroom and forcefully shoved resident's walker and resident onto the toilet, causing redness to the coccyx (small bone at the end of the spinal column) and injuring a staff member who was also in there. CNA stated they (the CNAs) have to work on the Alzheimer's units alone and are unsure what to do in an emergency. CNA stated the facility has a portable phone for use, but it is not always charged.*

Problem

Residents with Alzheimer's disease and/or dementia often develop behaviors that create risk to themselves and others. Failure to conduct behavior assessments/screening for residents prior to admission, not providing adequate supervision to ensure the safety of other residents, or not providing individualized therapeutic interventions for those residents with challenging behaviors may put the resident or other residents in danger.

Goal

Provide a safe environment, adequate supervision, and therapeutic interventions for those residents presenting challenging behaviors.

Approaches

1. Complete a thorough assessment prior to admission of the individual in his/her own home. Information should include physical health, medications, presence and intensity of pain, nursing procedures, mental and emotional health, behavior patterns that may be harmful to the individual or others (including destruction of property), risks (e.g., choking, falling, elopement), capacity for self-care and self-direction, activities within the community, and information about the individual's family. Any behavior assessment or plan previously developed and used for the individual should be included for reference. Assessment information should include available information from the individual's entire care team, including the delegated representative(s), case manager(s), behavior specialist(s), county client rights specialist(s), caregiver(s), physician(s) and mental health specialist(s).

2. Screen for offenders. Residents should be thoroughly screened for criminal offenses, including sex crimes, to determine history of violence, which is a key indicator of underlying aggression.

3. Train staff to be knowledgeable about crisis prevention/intervention. Staff should be knowledgeable about how to:
    - Recognize the warning signs and underlying sources of aggression.

- Identify types of behaviors that can signal impending violence, such as pushing, yelling, screaming, using offensive language, pacing back and forth, angry facial expressions, and continually calling out for someone.

4. Assist individuals with tasks they find unmanageable. Individuals with dementia often forget the order of simple tasks, such as dressing, putting on shoes, and brushing teeth. Utilize simple, one-step directions; break down tasks and instructions into clear, simple steps. Give directions one step at a time, and allow time for the direction to be followed.

5. Orient confused or agitated residents, frequently and gently, as to time and place. Have easy-to-read clocks and calendars. Pictures and labels can help to direct the person to the appropriate place, as well.

6. Approach individuals with dementia from the front whenever possible. They can be easily distracted and can become quickly overwhelmed in highly stimulating environments. This means that they may be startled when you move into view from the side. This stress may further interfere with their ability to see, hear, or comprehend.

7. Maintain consistent routines. Schedule personal cares, activities, and treatments at the same time and in the same order each day. Individuals with dementia find change difficult.

8. Consider whether the behavior may be caused by pain from other underlying medical conditions, e.g., osteoarthritis, history of hip fractures, other fractures, back pain, cancer, constipation, dental decay, migraine or headache, pressure ulcers, poor circulation to the lower legs.

   Behaviors indicating pain may include:

   - Wincing, groaning, or striking out when touched or moved
   - Tense body or resistance to movement or care
   - Loud and repeated calling out (e.g., asking for help)
   - Irritability
   - Rubbing of body parts, decreasing mobility, and increasing frequency of falls
   - Increasing confusion and decreasing language ability
   - Increased pulse, blood pressure, and sweating
   - Refusing food and biting lips

9. Speak calmly and respectfully; use first names to establish rapport. People with Alzheimer's and other dementias often have more difficulty expressing thoughts and emotions; they also have more trouble understanding others. Listed below are some ways to help the person with Alzheimer's communicate; a detailed list can be viewed at http://www.alz.org/care/dementia-communication-tips.asp.

   - Be patient and supportive; let the person know you are listening and trying to understand. Show the person that you care about what he/she is saying and be careful not to interrupt.
   - Use short, simple words and sentences, and do not overwhelm the person with lengthy requests or stories. Speak in a concise manner. Keep to the point. In some cases, slang words may be helpful.
   - Speak slowly and distinctly, and use a gentle, relaxed tone of voice – a lower pitch is more calming. Convey an easygoing, non-demanding manner of speaking. Be aware of your feelings and attitude, as they are often communicated through your tone of voice.
   - If s/he is having trouble communicating, let the person know that it's okay. Encourage the person to continue to explain his/her thoughts.
   - Avoid criticizing or correcting. Never tell the person that what s/he is saying is incorrect. Instead, listen and try to find the meaning in what is being said. Repeat what was said if it helps to clarify the thought.

If the person says something you do not agree with, let it be. Usually, arguing only makes things worse, often heightening the level of agitation for the person with dementia.

10. Provide individuals with an opportunity to rummage and make rummaging a stimulating, safe activity. Rummaging, hiding, and hoarding are all behaviors an individual does to gain a sense of security. Hiding or hoarding items is an attempt to make them feel safe.

Challenging Behaviors Resources

- Wisconsin Music and Memory Program
https://www.dhs.wisconsin.gov/music-memory/index.htm
- Challenging Behaviors (September 2011) Alzheimer's Association
http://www.alz.org/documents_custom/statements/challenging_behaviors.pdf
- Communication – Best ways to interact with the person with dementia (2005) Alzheimer's Association
http://www.alz.org/documents/greaterillinois/Communications.pdf
- Dementia and aggressive behavior, Alzheimer's Society
http://alzheimers.org.uk/factsheets
- Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes (2009) Alzheimer's Association
https://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf
- Rummaging, Hiding and Hoarding Behaviors (2012) Alzheimer's Association, St. Louis Chapter
http://www.alz.org/stl/documents/HoardingRummaging.pdf
- Centers for Medicare & Medicaid Services, Review of Care and Services for a Resident with Dementia
http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-13-35.pdf
- Dementia and Aggressive Behavior, *Dementia Today,* June 27, 2011
http://www.dementiatoday.com/dealing-with-aggressive-behavior/
- Ellison, J. and Hsu, D. (2014, April 15) A Dark Side of Dementia Care**,** Published on Psychiatric Times,
http://www.psychiatrictimes.com/dementia/dark-side-dementia-care
- Fishkind, A. (2002, April) Calming agitation with words, not drugs, *Current Psychiatry*, Vol.1, No. 4
- Resident-on-Resident Aggression: Identifying Danger Signs, Defusing Conflict, *CNA CareFullySpeaking, a risk management resource for aging services*, 09 Issue 1
https://www.cna.com/vcm_content/CNA/internet/Static%20File%20for%20Download/ResidentonResidentAggressionIdentifyingDangerSignsDefusingConflict.pdf
- Violence Prevention: Identifying and Addressing the Risks, *CNA CareFullySpeaking, a risk management resource for aging services*, Republished 2014
https://www.cna.com/vcm_content/CNA/internet/Static%20File%20for%20Download/Risk%20Control/Medical%20Services/RC_Med_Article_ViloencePrevention-IdentifyingandAddressingtheRisks_2014.pdf
- Resident-to-Resident Aggression in Long-Term Care Facilities: Insights from Focus Groups of Nursing Home Residents and Staff, J Am Geriatr Soc. 2008 August ; 56(8): 1398–1408. doi:10.1111/j.1532-5415.2008.01808.x.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2755096/
- Soreff, S. and Siddle, D. (March 2004) Understanding and dealing with resident aggression, Techniques for managing a delicate situation, *Long-Term Living*
http://www.ltlmagazine.com/article/understanding-and-dealing-resident-aggression

- Stephen Soreff (2012). Violence in the Nursing Homes: Understandings, Management, Documentation and Impact of Resident to Resident Aggression, *Essential Notes in Psychiatry* http://cdn.intechopen.com/pdfs-wm/36297.pdf
- Wisconsin Circuit Court Access http://wcca.wicourts.gov/index.xsl;jsessionid=AD1BF8106034C43F3056D2524806628F.render6
- Wisconsin Department of Justice, Division of Law Enforcement Services, Background Check & Criminal History Information http://www.doj.state.wi.us/dles/cib/background-check-criminal-history-information
- WI Sex Offender Registry http://doc.wi.gov/community-resources/offender-registry

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SEXUAL BEHAVIOR

Examples

- *A female resident was admitted with diagnoses of "Alzheimer's, dementia without behavioral disturbance, vascular dementia, depression, and a history of strokes." Medical record "indicates the resident did not care plan any problematic, affectionate, or distressing behaviors" at the time of admission. She began seeking out a particular resident and was constantly affectionate toward him – holding his hands, kissing him on his hands and lips, and going into his room while he was sleeping and waking him up. Neither he nor his power of attorney was happy with her behavior. Staff had to intervene at times because she would not let go of his hands when he wanted to leave. The facility implemented a behavior monitoring tracking form. In a period of 10 days, the female resident attempted to be affectionate toward him 82 times.*

- *Two residents with dementia were found together unclothed and in bed. The male resident had his hand in the female's genital area. Staff separated the two, dressed them, and placed them on 15-minute checks. Three days later, the two residents were found again in bed and unclothed. When separated, the two became very upset. On another occasion, the two residents were again found in bed and unclothed. The male resident had his hand in the female's genital area. When separated, the female resident asked, "What did I do wrong? I'm so sorry." She thought he was her husband. The male resident has been noted to be inappropriate on several times – asking staff for a kiss, to go to bed with him, to stay with him tonight. The male resident was found on three different occasions with three other female residents, with his pants down and leaning over each one.*

Problem

Failure to apply fundamental principles of care for persons with dementia, not focusing on the need for affection or intimacy, lack of supervision to protect vulnerable residents, and not assessing/screening residents prior to admission may often result in the development of sexual behaviors that can create a risk to themselves or other residents in the facility.

Goal

Affirm and respect the rights of all residents to engage in consensual relationships. At the same time, a facility should acknowledge its responsibility to protect residents who may not be able to consent to sexual relationships.

Approaches

1. Conduct a thorough assessment of the physical, mental, and social history of the resident directly upon his or her admission to the facility. This may help staff to identify the resident's lifetime patterns of behavior or needs. The information gleaned from the assessment should be used to determine why the resident's behavioral symptoms are problematic; whether, and to what extent, the behavior places the resident or

others at risk for harm; and any related contributing and/or risk factors. Develop an individualized care plan based directly on these conclusions. The focus of the care plan should be to address the underlying cause or causes, reduce the frequency of truly problematic behaviors, and minimize any resultant harm.

2. Screen for offenders. Residents should be thoroughly screened for criminal offenses, including sex crimes, to determine history of violence, a key indicator of underlying aggression.

3. Develop a "resident relationships" policy in order to affirm and respect the rights of all residents living in the facility to engage in consensual relationships, whether professional, platonic, married, non-married, intimate, or sexual in nature. The policy should uphold the belief that healthy, consensual relationships are central to quality of life and promote an environment that allows individuality, autonomy, dignity, and respect to thrive. At the same time, a facility should acknowledge its responsibility to protect residents who may not be able to consent to sexual relationships.

4. Train all staff in the facility regarding the effect dementia has on a person's impulse control. Staff should also be trained to observe behavioral/physical signs of distress and to identify what may trigger sexual responses by residents so that behaviors can be minimized or prevented from reoccurring.

5. Protect the dignity and worth of the residents, and maintain self-determination as to their sexual activity. Restricting and denying the residents' relationships and sexual encounters diminishes the self-determination and dignity of the person. Staff should honor and support the choices made by a resident, unless it leads to harming oneself or others.

6. Assess the ability of residents with dementia to engage in different types of intimate and sexual behavior. Some residents with dementia may be able to consent to participate in intimate behaviors, while others may lack the ability to consent. Assessment efforts should focus on the resident, with the understanding of the following guidelines:
   - A person with dementia must be able to make a voluntary decision, without coercion, to participate in a sexual relationship. Residents should be able to tell staff in his/her own words or actions.
   - A person must also have the ability to say "no," or otherwise indicate a refusal or rejection of someone's sexual overtures. Staff often can identify if a resident with dementia is doing something of his/her own free will. Residents should be able to tell staff in his/her own words or actions.
   - Residents must also have the ability to be safe from physical or emotional harm, which includes sexually transmitted diseases.
   - A person with dementia must be able to understand there may be negative societal response to the conduct (gossip, name calling, social fallout, stigmatization).

Sexual Behavior Resources

- Alzheimer's Association Southeastern Wisconsin
  Capacity and Consent in Intimacy and Sexuality in Dementia Care
  http://www.alz.org/sewi/in_my_community_professionals.asp

- Loddon Mallee Regional Dementia Management Strategy
  Preventing and managing sexual disinhibition or inappropriate sexual behaviour.
  http://www.dementiamanagementstrategy.com/Pages/ABC_of_Behaviour_Management/Management_Strategies/Sexual_Disinhibition.aspx

- Long-Term Care Facility Resident Assessment Instrument User's Manual
  http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/MDS30RAIManual.html

- Scott, C., State Long-Term Care Ombudsman, et al (Spring 2009). Considerations Regarding the Needs of Long-Term Care Residents for Intimate Relationships and Sexual Activity
http://theconsumervoice.org/uploads/files/events/Handout-Needs-of-LTC-Residents.pdf
- Wisconsin Board on Aging and Long Term Care Ombudsman Program
Resident Relationships Guidelines
http://longtermcare.wi.gov/docview.asp?docid=25735&locid=123
- Wisconsin Board on Aging and Long Term Care Ombudsman Program
Appendix 1 – Recommendations for Addressing Resident Relationships: Intimacy & Sexuality History
http://longtermcare.wi.gov/docview.asp?docid=25736&locid=123
- Wisconsin Board on Aging and Long Term Care Ombudsman Program
Appendix 2 – Recommendations for Addressing Resident Relationships: Assessment for Consent to Physical Sexual Expressions
http://longtermcare.wi.gov/docview.asp?docid=25737&locid=123
- Wisconsin Circuit Court Access
http://wcca.wicourts.gov/index.xsl;jsessionid=AD1BF8106034C43F3056D2524806628F.render6
- Wisconsin Department of Justice, Division of Law Enforcement Services, Background Check & Criminal History Information
http://www.doj.state.wi.us/dles/cib/background-check-criminal-history-information
- WI Sex Offender Registry
http://doc.wi.gov/community-resources/offender-registry