



Center for Excellence in Assisted Living (CEAL) comments submitted to the Centers for Medicare and Medicaid Services (CMS) on guidance implementing the HCBS Final Rule: person-centered dementia care in assisted living

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The Center for Excellence in Assisted Living (CEAL) appreciates this opportunity to continue the dialogue with CMS regarding the most appropriate guidance to states and providers regarding implementing the 2014 final rule on Medicaid-funded home and community-based services (HCBS). These comments will further elaborate on earlier comments that the CEAL submitted to CMS, especially regarding some approaches to person-centered care (PCC) for residents living with dementia in assisted living.

An estimated 5.4 million Americans currently have [Alzheimer's disease](#), the most common cause of dementia, and many additional people have other types of dementia from a host of other causes. As the nation ages, the number of older people with Alzheimer's disease is projected to increase to 7.1 million by 2025 and to 13.8 in 2050. Family caregivers are the first line of support for people with dementia. In 2015 over 15 million family caregivers of people with dementia provided an estimated 18 billion hours of unpaid care, which would have cost \$221 billion to replace with paid services. But many family caregivers are stretched to capacity, and [projections](#) indicate a growing shortage of family caregivers compared to the likely increase in demand for support. Paid services will have to play a growing role in providing services to the growing population living with dementia; indeed, dementia care communities have been the fastest growing segment of the assisted living industry in recent years.

To meet this increased demand through PCC services, CEAL recommends once again three documents that CEAL has produced in recent years in collaboration with researchers from the University of North Carolina. We believe these documents represent some of the best evidence-based guidance on how to translate the principles of person-centered care into observable and replicable practices that providers can build into their daily operations. These three documents demonstrate CEAL's commitment to achieving the HCBS attributes essential to person-centered care and may serve CMS and states well as they develop specific guidance on implementing the HCBS rule:

- ["Person-Centered Care in Assisted Living: An Informational Guide"](#) – a conceptual framework for identifying HCBS attributes and person-centered care;
- ["Person-Centered Care Domains of Practice: General Home and Community-Based Services Attributes and Assisted Living Indicators"](#) – which translated the conceptual framework into observable outcomes; and
- ["Toolkit for Person-Centeredness in Assisted Living: An Informational Guide and Questionnaires of Person-Centered Practices in Assisted Living \(PC-PAL\)"](#) – which provide specific guidance on PCC to providers in their daily operations.

In preparation for these comments, we reached out to some of the leaders in providing PCC to assisted living residents living with dementia. In these discussions, three important themes emerged that may help states and providers identify strong PCC attributes when serving people living with dementia.

Theme #1: If individual, PCC planning and delivery is important for every person, it is doubly important for those people living with dementia.

The very helpful statement of purpose from the CMS online [Fact Sheet](#) entitled “Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule” provides a useful baseline for evaluating services for people living with dementia –

“In this final rule, CMS is moving away from defining home and community-based settings by ‘what they are not,’ and toward defining them by the nature and quality of individuals’ experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting’s location, geography, or physical characteristics.”

Understanding “the nature and quality of individuals’ experiences” is especially critical when it comes to providing PCC planning and delivery for people living with dementia. As we noted in our previous comments, “the nature and quality of individuals’ experiences” change over time as people age, especially when they experience the loss of a spouse, the distance of children, changes in their surrounding communities, and changes in their underlying health conditions and disability status. The progressive cognitive losses associated with dementia particularly highlight the changing experience of home and community, presenting challenges to providers seeking to promote the best quality of life for people living with dementia. Our comments seek to include examples of good practices, but we still have much to learn about how to serve people living with dementia. While the research base is growing, we encourage CMS to provide the flexibility for innovation in this rapidly evolving area of services.

A [literature review from the Administration for Community Living](#) (ACL) provides one of the best summaries of person-centered care principles for people living with dementia:

- “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.”

In our discussions with distinguished leaders in providing services to people living with dementia, the most common underlying theme was the absolute necessity of getting to know each individual and tailoring PCC plans and service delivery according to each individual’s needs and preferences. Research on providing services to people living with dementia can provide useful guidance to providers. The [Alzheimer’s Association](#) has provided widely supported approaches to effective PCC planning and delivery in residential communities serving people living with dementia. Experts agree that no “one size fits all” approach will be successful. There is no substitute for understanding what each individual needs

and prefers when it comes to feeling comfortably at home and remaining engaged in communities they find meaningful.

Guidance Language to Operationalize PCC Planning for People with Dementia:

Sections (c)(1) and (c)(2) of the HCBS final rule describe in detail the person-centered service planning process and the content expected. The rule emphasizes that “The individual will lead the person-centered planning process where possible.” The cognitive limitations characteristic of dementia may make it more complicated for the resident to lead the planning process, but providers must nonetheless involve the resident to the extent possible in the planning process. Even where representatives of the residents are involved in the planning process as provided by the rule, providers must make efforts to communicate service options clearly in a way that each resident can understand and solicit and document their preferences. The fact that a resident has difficulty making decisions in some areas related to their service needs does not mean that they cannot express meaningful preferences in other areas. Residents may be capable of making many decisions, even if representatives are needed regarding some decisions.

When documenting decisions about service options and preferences, providers should note when the agreed upon decision reflects the expressed preference of the individual and when it reflects a decision made by the resident’s representative. In cases of disagreements between the residents and their representatives, the provider should note the disagreement and any accommodations offered to mediate those differences. Ordinarily, providers should defer to the preferences expressed by the resident in such circumstances unless there are compelling reasons not to do so. If the provider elects to defer to the resident’s representative or includes an option other than the preference expressed by the resident, then the provider must document why that decision was made and what alternatives were offered as provided in the rule.

Practices that providers should adopt to demonstrate acceptable person-centered dementia services planning include:

- *Service plans that are uniquely tailored to the needs and preferences of each individual resident;*
- *Service plans that show evidence of meaningful involvement of the resident in the discussions or decisions related to the services he or she receives;*
- *Service plans that show evidence that residents were offered alternative service approaches designed to meet their individual needs and preferences;*
- *Service plans that defer to decisions made by the resident or their designated representative.*
- *Service plans that discuss individual preference for community integration within and outside the residential setting and how the provider will assist in that integration through provider assistance, flexibility in scheduling meals/medication administration/personal care services, and provider coordination of 3rd party and volunteer services.*

Theme #2: A corollary to the first theme is that effective PCC delivery must rest on effective communications with residents living with dementia that is grounded in building relationships, not just providing needed services.

The key to any PCC is effective communication of needs and preferences between providers and residents. Such communication may be more difficult, but may be even more necessary, when the resident is living with dementia and their ability to communicate through conventional means may be compromised. In our brief survey of the literature and interviews with leaders in providing PCC for people living with dementia, five major points emerged related to communication:

- Listening – It may seem obvious that communication requires listening, but it is far too common that what people living with dementia say is dismissed because of their cognitive impairment. Even if the communication seems garbled or “out of touch” with reality, what people living with dementia have to say can provide important clues regarding what they are feeling and experiencing.
- Observing – Careful observation of patterns of behavior, potential sources of frustration or discomfort, and emotional clues is one of the skills that almost every interviewee raised in our discussions. The clues to understanding each person’s behavior are highly individual and often subtle, so staff must take the time to interact and observe each resident on a regular basis.
- Learning about each individual’s life story – Knowing details from residents’ life stories is critical to giving context to what they say and what they do. The ACL report above cited the example of a former mail carrier who was entering other residents’ rooms invited. That behavior ceased when staff started leaving “mail” outside each room that the man could collect and deliver each day. One provider we interviewed cited an example of a man who wanted to leave the building late each afternoon. It turns out that he was a farmer who checked on the cows each day. When he was allowed to exit, he would check a nearby field and then return.
- Interpreting what is seen and heard – Understanding and interpreting what residents say and what they do requires staff to see the world from the perspective of the resident. As one provider’s training materials put it: “All behaviors are a form of communication, it is up to caregivers to determine the message. To determine what is being communicated, caregivers need to meet the individual in their world.”
- Relating to each resident as an individual – The communication attributes listed here can be summarized by saying that each resident should be treated and respected as an individual. One provider cited an example of a woman who had displayed problematic behaviors with all but one direct care worker. That care worker reported that her “intervention” was simply to say “thank you” each time the resident allowed services to be provided such as grooming or dressing. Other respondents reported using music to communicate with residents and make them feel comfortable and at home.

Several sources noted that key to successful communication was embedded in the roles and expectations related to the direct care staff members who had the most extensive contact with residents. Indeed, good communication with residents should extend to good communication with and

respect for family caregivers and direct care workers. Involving direct care workers in regular staff meetings where their observations are noted and their judgment respected is critical to making certain that resident preferences are honored in daily operations. A number of sources stressed that direct care workers need support for spending time with residents and clarity that their main task is not just the services they provide but the relationships they build.

Education about the nature of various causes of dementia and the course they take can help staff identify the sources of some problems and provide strategies for dealing with them. Staff members at all levels need such education, whether or not the residential community is specifically designated for people living with dementia. Virtually all assisted living communities house residents with various stages of dementia whether or not they are designated or licensed for specialized dementia services. Providing good PCC for such residents in general assisted living communities can enable people living with dementia to stay in their homes longer and avoid being forced into institutional environments.

Guidance Language to Operationalize Good Communication with Residents

Evidence of promoting good communication with residents must go beyond recording resident preferences in regularly updated PCC plans as important as that is. Daily communications among staff members and records kept by providers should include the expressed preferences from residents, observations about what seems to give residents comfort and what seems to increase frustration and agitation, and interventions that seem to work and not work in addressing the perceived messages from each resident.

The provider's policies and procedures should also reflect the emphasis on good communication with residents, especially when it comes to the roles and expectations for direct care staff. Policies and procedures should make it clear that direct care workers are expected to spend time getting to know each resident as an individual. Daily records should include insights from direct care workers regarding individual resident needs and preferences.

In order to promote effective communication that is the core of PCC planning and service delivery, management should provide education and training materials regarding ways to communicate with residents living with dementia. Training programs should include important information on issues such as:

- *Types of dementia, their causes and how they affect the individual's ability to function;*
- *Stages of dementia and what to expect over time;*
- *Principles of person-centered care planning and service delivery;*
- *Strategies for handling behavioral expressions of need or distress.*

Theme #3: Good communications and PCC planning and service delivery can mitigate behavioral expressions of need or distress that are often misunderstood and labeled as abnormal or anti-social, including unsafe exit seeking, but safety concerns may require some form of secured egress from buildings.

A common manifestation of dementia is walking about, often referred to as “wandering” behavior – indeed, the Alzheimer’s Association reports that six in ten people with Alzheimer’s disease will engage in “wandering” behavior at some point in the course of the disease. People with dementia who are walking about may appear to be engaged in purposeless “wandering”, but to the individual, such walking about is often linked to purposes that are clear to them. Best practices should be employed by providers to understand walking about behavior, minimize potentially dangerous exiting seeking (sometimes referred to as “elopement”), and allow for access to the outdoors and safe walking. The high risks and the unpredictable nature of exit seeking, however, do suggest the need for special measures to assure the safety of residents. Uncontrolled egress has resulted in unnecessary tragedy in some cases. Many times, a move to dementia-specific assisted living occurs when the family cannot meet the needs of the person affected by the disease and when they are no longer safe in their own homes because they are at heightened risk of unsafe exit seeking.

Behavioral expressions of need or distress, in particular exit seeking, demonstrate some of the most challenging issues and trade-offs that must be made in residential communities that serve people living with dementia. Such behaviors also illustrate the critical importance of PCC planning and delivery as described above in effectively addressing the underlying causes in each individual case. Even very effective and dedicated programs for providing PCC for people living with dementia noted that they employ ways to secure egress from the building to address safety concerns, but they stressed that secured egress alone is not an adequate response to exit seeking behaviors. Some noted that states often require secured egress in buildings that specialize in dementia care.

PCC for people living with dementia must start with the understanding that exit seeking is not just a safety issue to be dealt with by ways to restrict the individual or the entire community; exit seeking motivations must be understood from the perspective of each individual. As the [Dementia Practice Guidelines](#) from the Alzheimer’s Association note, “The behavior and emotional state of people with dementia often are forms of communication because residents may lack the ability to communicate in other ways.”

Exit seeking may be common among people living with dementia at some point in the progression of the disease, but it is not universal and the reasons motivating exit seeking vary with each individual. Behavior that may appear to be aimless “wandering” or dangerous “elopement” to the outsider may have many meanings to different individuals and for each individual at different times. (See the [ACL report](#) cited above for a discussion of these motivations.)

- For some, exit seeking may simply be an attempt to have a pleasant walk, to get outside and get a bit of exercise.

- Exit seeking may also be motivated by human needs that the person may have difficulty communicating, such as the need for human interaction or hunger or thirst.
- Some exit seeking may be related to patterns of daily routines and types of community engagement that may have been disrupted by the move to assisted living.
- Some exit seeking may be an attempt to express distress regarding aspects of the residential environment, such as noise, other residents, and restrictions on access to exterior spaces or unpleasant interactions with staff members.

Each of these types of motivations for exit seeking requires a different type of response. Examples of the types of programs that could be offered to residents living with dementia include: fitness, yoga/mediation, cognitive stimulation, aromatherapy, pet therapy, music intervention, spiritual programs, leisure programming, community involvement through outings and service experiences, and more. These opportunities play a vital role in improving and maintaining the quality of life of people living with dementia and can create a possibility for enhancing the level of their daily functioning and for [preventing the manifestation of loneliness, boredom, and the “problem behaviors” often associated with dementia](#). Furthermore [recent studies](#) suggest that addressing stress, sleep, and diet in combination with additional clinical therapies can produce an improvement in cognitive symptoms significant enough to enable people living with dementia to engage more successfully in normal daily activities.

Residents in assisted living communities should be encouraged to walk with safe walkways within the building and safe spaces outdoors. Understanding signals of needs or distress are skills that come from staff communicating with residents on a regular basis. Similarly, understanding the person’s history, their routines, and their communities of engagement can help plan for ways to address those routines and relationships. A whole science of environmental design and modifications is developing to create physical spaces, lighting, and cuing that are inviting and reduce frustrations. The respondents we interviewed also spoke of using staff, family caregivers, and volunteers to enable people to remain engaged in their communities – though such activities require advance planning and do not address spontaneous desires to leave the building. Moreover, staff limitations, especially in communities relying on Medicaid reimbursement levels, restrict how much time staff can devote to individual desires to engage in activities outside of the community.

In short, each of these motivations for exit seeking require a focus on the individual, cultivated relationships and good communications, as well as education about strategies for addressing the underlying needs and preferences that motivate the exit seeking. Nonetheless, a characteristic of dementia is diminished capacity to make important judgments, including when exit seeking is unsafe. Even the most committed provider of PCC cannot eliminate the risks of all exit seeking, and all of the providers we interviewed had some form of controlled egress. As the ACL report notes, one of the goals of person-centered dementia care must be to “Prevent unsafe wandering or exit-seeking.” [Research in this area](#) remains sparse and many issues remain unresolved, including:

- The use of technology: Some providers saw some promise in technologies – such as fobs or electronic code pads – that can selectively control egress for those who are identified as having a higher risk and allow family and friends to come and go freely. However, our interviewees cautioned that technology is never the complete answer in the absence of some of the PCC practices outlined above. Several stressed that some technologies can exacerbate problems, such as wearable technologies that residents sometimes resist wearing or loud alarm systems triggered by attempts to exit. Interviewees generally thought that technological assistance with controlling unsafe exit seeking was a work in progress.
- Controlled sections within buildings or communities: One continuing care retirement community (CCRC) reported that it did not have secured egress from its dementia care unit. The residents were free to visit other parts of the CCRC and participate in the activities there. Security for the entire CCRC was sufficient in this kind of community to prevent unsafe exit seeking.

Guidance Language for Addressing Exit Seeking and Other Dementia-related Behavioral Expressions of Need or Distress

People living with dementia who exhibit exit seeking and other unpredictable behavioral expressions of need or distress should be addressed in a person-centered manner. Providers should seek to identify the individual's reasons for such behaviors and develop an individualized, person-centered plan that includes meaningful strategies to help respond to the underlying needs in order to alleviate, discourage, or redirect the behavior. Residents must have safe opportunities for walking, both within the building and in exterior spaces. To the extent possible, providers should address the motivations for exit seeking in ways that honor the individual's preferences and needs. Each resident must have regular provider-facilitated opportunities to participate in community activities in the broader community if they choose. Environmental modifications, changes in roommates or modifications in the timing of services and activities may be part of the plan to address each resident's needs and preferences as reflected in their exit seeking behavior.

Providers remain responsible for the safety of the residents in their buildings. All providers should have plans that deal with unsafe exit seeking behaviors, including plans in the event that a resident becomes lost through unsafe exiting. Controlled egress may be necessary to assure the safety for those who are at risk of unsafe exit seeking. Residential communities with secured egress must make individual determinations regarding residents for whom unrestricted egress would be unsafe. Such a determination must be documented in the person-centered services plan and reviewed periodically to make certain that such restrictions continue to be necessary. Providers can demonstrate in a variety of ways that they permit egress for residents who are not at risk of unsafe exit seeking. In some cases, wearable technologies may permit egress among those residents who have not shown a risk of exit seeking while restricting the unsafe exiting of those who have shown such a risk. Family and frequent visitors must be given unrestricted access as with any other assisted living or independent living community. Residents must have unrestricted access to secured outdoor spaces or regular escorted access to locations and activities outside of the community as provided in the person-centered services plan. Providers with

secured egress must have systems that automatically provide unrestricted egress in the event of a fire or other life safety event in accordance with local building codes.

Conclusion

Providing person-centered services to people living with dementia presents some of the most challenging issues in promoting the objectives of honoring individual preferences and enabling community engagement as required by the final HCBS rule. The cognitive impairments characteristic of dementia often limit the ability to communicate preferences, to recognize realistic choices, and to exercise judgment about the safety and risks associated with behaviors. Person-centered approaches are doubly important in serving residents with such limitations to develop individualized plans and strategies that acknowledge the personhood of each individual.

At the same time, those who move to residential communities such as assisted living for services are often those whose cognitive limitations have made it difficult to remain in their own homes and communities safely. Even where providers make extraordinary efforts to provide the best person-centered services, living in a residential environment inherently changes the experiences of home and community. Good PCC can enhance the individual's sense of comfort at home and engagement with a community, both within the assisted living community and in the broader community for those who may have become increasingly isolated because of their disabilities. Some features of residential life, such as controlled egress, may place some limitations on personal freedom. However, denying Medicaid HCBS funding on this basis would only mean that residents are forced into more restrictive institutional settings that generally do not have the same PCC requirements or orientation. CMS must make some balanced judgments in this area regarding the trade-offs between personal choice and safety.

Once again, the CEAL appreciates this opportunity to engage in this dialogue with CMS regarding the guidance to states and providers in implementing the final HCBS rule. CEAL once again applauds the effort to place consumer needs and preferences in the center of the planning and delivery of supportive services at a time of rapid change in the delivery of health and long-term supportive services. We look forward to further discussions, either in a formal way through an ongoing multi-stakeholder workgroup to address issues in assisted living or through periodic meetings and exchanges of ideas.