



Person-centered care and dementia

Best practices for residents living in long-term care

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ACCORDING to the Alzheimer's Association, approximately 5.7 million Americans have Alzheimer's dementia, and that number is expected to grow. The progressively debilitating nature of the disease causes patients to lose the ability to live independently, so many rely on long-term care services. In the United States, about 1.4 million residents live in long-term care facilities; 50.4% of them have been diagnosed with dementia.

To receive Medicare and Medicaid funding, long-term facilities must comply with federal regulations that require them to promote residents' quality of life and to preserve their dignity and self-determination. This includes allowing residents the opportunity to participate in the development and implementation of a person-centered care (PCC) plan.

What is PCC?

PCC incorporates knowledge and recognition of an individual's life history, beliefs, values, needs, and preferences as the central influences on how caregivers interact with them. Personhood and selfhood are fundamental to PCC.

Personhood is a standing or status bestowed on an individual by others. Personal affirmation provided by relationships with others is essential for maintaining personhood.

Selfhood is defined as the attributes, characteristics, beliefs, and desires of the self. It al-

so includes an individual's roles and how they present themselves publicly. For those with dementia who live in long-term care, staff members can provide these personal affirmations. Lack of support for personhood can damage a vulnerable person's self-esteem and lead to loss of selfhood.

Best practices in dementia care

A growing body of evidence suggests that personhood and selfhood aren't lost in dementia. Behaviors that were once thought to be solely the result of dementia's neuropathology are now viewed as a complex interaction with socio-psychological factors. Evidence from the Crisis Prevention Institute indicates that individuals with dementia maintain abilities at every stage of the condition. Those abilities can be used to maximize function and well-being and to promote social and leisure activities that positively impact activity levels and mood. Behaviors such as wandering, agitation, and resistance to care aren't viewed as normal manifestations of dementia, but rather as expressions of a problem that can be minimized with best practices.

Ensuring quality of life for people with dementia begins with having accurate knowledge about the disease and an understanding of PCC principles.

- Recognize that people with dementia continue to express aspects of themselves (selfhood) in many ways, even as dementia progresses.
- Emphasize understanding behavior rather than managing it.
- Allow residents to exercise choice, use their abilities, express their feelings, and develop and maintain relationships.
- Make PCC the foundation to quality care.

Implementing best practices must include staff training. However, changing attitudes and beliefs about individuals with dementia can be challenging. Storytelling techniques actively engage staff in the experiences of others by asking them to imagine, embrace, listen to, and connect with the person who has dementia. "Let's talk about it" (era.lib.ed.ac.uk/handle/1842/6559) is a downloadable toolkit that can be used for this type of staff training.

PCC benefits

Systematic review and meta-analysis of current evidence indicate that adopting a PCC ap-

Sample life story questions

To learn more about a resident's life story, consider asking these questions.

- Can you tell me about your school days when you were a child?
- Who was important to you when you were growing up?
- What was it like growing up where you lived?
- What music did you listen to, and what music do you like now?
- Can you tell me about your first movie? First date? First job?
- Can you tell me about important life celebrations, such as birthdays, holidays, and graduations?
- Can you tell me about a difficult time in your life and how you adjusted?
- How would you like to be remembered?

proach can benefit long-term care facility residents and staff.

Resident benefits

Studies, including one by Chenoweth and colleagues, show that PCC can significantly reduce behavioral disturbances (such as aggression and agitation) and neuropsychiatric symptoms of dementia. When these behaviors are reduced, use of psychotropic medication also can be reduced, which aligns with the Centers for Medicare and Medicaid Services' goal to decrease unnecessary use of antipsychotic medications in long-term care facilities.

Staff benefits

PCC training and education prepares staff to respond more effectively to the challenging situations that can occur when caring for residents with dementia. The result is lower staff stress and burnout and higher job satisfaction. However, according to Moyle and colleagues, staff who practice PCC will need opportunities to reflect on and deal with their emotions, workload, and time management. Support systems should be implemented to assist staff with balancing increased engagement with residents while maintaining professional boundaries.

PCC strategies

Many strategies can help caregivers implement PCC. Some of the most common approaches (and recommended resources) are described below.

Know the person

Life story work involves working with a resident and their family members to learn about the person's life, recording that information in some way, and then incorporating it into the resident's care.

Reminiscence therapy, frequently conducted in informal settings with other residents,

Communication tips

Use these tips to communicate effectively with residents who have dementia.

- Always attempt to find the meaning of a resident's behavior. For example, boredom and frustration frequently are communicated through behavior. In patients with more advanced dementia, behavior can signal unmet needs such as being cold, hungry, or frightened.
- Remember that communication is more than words. It includes gestures, body posture, and movements, which can be misinterpreted by people with dementia.
- Explain what you're going to do before touching a resident, and give them time to respond.
- If the environment is too stimulating, some residents may need to withdraw to a quiet area.
- Knowing the person helps you understand their behavior.
- Try not to take bad behavior personally or judge it.
- Don't use force to control a patient's behavior.
- Keep in mind that communication is never a waste of time, even if you have other things to do.

involves sharing autobiographical memories. Themes to explore include food and cooking, family relationships, early memories, jobs, music, celebrations, and losses. (See *Sample life story questions*.)

To capture reminiscence activities, consider recording them in a life storybook (hard copy or digital), a written summary, or a memory box. The resident and family can use these to talk about life experiences, which will provide staff with insight into residents' personal interests, values, beliefs, and culture. Hearing a resident's life story can help staff see the person as an individual and develop a deeper relationship. Reconstructing and recording narratives from fragments of stories told over time by the resident with dementia also can help staff members get to know the person.

Recommended resources: Arts-and-crafts supplies and interview questions. Much of the information needed can be obtained in the admission and care planning process.

Effective communication

Staff may think that they don't know how to communicate effectively with people who have dementia. They also may assume that someone with dementia can't communicate or that it takes too much time. This sets the stage for nonengagement, which perpetuates withdrawal by both the resident and the caregiver, leads to caregiving without communicating, and prevents relationship building. Difficult behavior frequently is the result of miscommunication and unmet needs, leading to a cycle of misunderstandings and more difficult behavior.

Breaking this cycle improves everyone's quality of life and reduces the need for psychotropic drugs. (See *Communication tips*.)

Recommended resources: Stephen Miller's *Communicating Across Dementia: How to Talk, Listen, Provide Stimulation, and Give Comfort* can be purchased as an e-book. This low-cost resource is easy to use for all levels of staff development training, including housekeeping, dietary, and nursing.

Concept mapping

A concept map is a visual representation of ideas or knowledge, including the links between them. It involves a person-centered assessment and problem-solving approach to managing behavioral and psychological symptoms of dementia. When completed by an interprofessional team (nurses, pharmacists, and occupational, physical, and recreational therapists), concept mapping can effectively identify what's known and unknown so the team can get a new perspective for providing the best care.

Concept mapping starts with writing all available information and assessment data on a board, using predetermined categories (such as life history, dementia stage and current behaviors, health status, communication ability, and environment). Categories can be individualized as needed. After mapping is completed, missing information and links between categories become apparent. The goal is to understand the behavior and identify unmet needs so the team can develop individualized care strategies. (See *Concept mapping in action*.)

Recommended resources: Team meeting, patient information, white board, and markers.

Environment and activities

Multisensory environments that support sensory therapeutic activities are recommended for individuals in all dementia stages. Having a variety of activities that can be self-chosen supports personhood rather than using a one-size-fits-all approach. Activities can include drama, art, music, and dance. Some residents may enjoy hand massage and aromatherapy. Everyday tasks within a resident's abilities—such as making coffee, setting and clearing a table, cleaning, pairing socks, or watering plants—are associated with resident quality of life in long-term care. Providing dusters, dolls, soft toys, handbags, jewelry, musical instru-

Concept mapping in action

These examples of residents (names are fictitious) in long-term care illustrate how concept mapping can help staff implement person-centered care (PCC).

Case history	Behaviors	PCC approaches
Eugene		
<ul style="list-style-type: none"> Late-stage dementia Friendly and outgoing with lots of energy; likes to sing Has trouble communicating his needs Daughter states he loves old-time country music and used to be a hunter 	<ul style="list-style-type: none"> Frequently walks unattended and falls Becomes agitated when not kept busy by the staff 	Staff provide <ul style="list-style-type: none"> a standing walker with a seat so he can safely ambulate an MP3 player with his favorite music hunting magazines.
Mary		
<ul style="list-style-type: none"> Moderate-stage dementia Enjoys social activities Affectionate and pleasant Was a social worker Likes to help others 	<ul style="list-style-type: none"> Becomes distressed when she doesn't know what to do next 	Staff: <ul style="list-style-type: none"> provide her with direction for doing simple tasks and let her know how much she's helping encourage her to help during social activities, such as passing out items and collecting them.

ments, bubbles, and puppets can spark interest and engagement.

Recommended resources: Donations of items can be sought from groups such as the Girl Scouts, places of worship, and families. Therapists can help evaluate individual residents' personal abilities to promote the highest level of function.

Make the commitment

PCC is an expected standard of care, but it can be difficult to maintain. Effectively influencing the attitudes and behaviors of staff about PCC can be challenging, as can restructuring the work environment and culture. Successfully implementing PCC requires a commitment by all stakeholders, which includes providing further education and adequate resources to develop, deliver, and sustain the practice. **AN**

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