

# The Human Factor: Person-Centered Care Strategies for Senior Care Residents Who Have Dementia

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Healthcare providers and staff members who work in senior care organizations face unique challenges in caring for the aging population, including managing residents who have multiple health conditions, take numerous medications, and might suffer from various physical and cognitive declines.

One common, but complex issue facing senior care workers is providing competent care for residents who have dementia. Dementia refers to a group of symptoms that affects cognitive and behavioral functions and interferes with a person's ability to perform standard daily activities. Dementia can affect a person's ability to think, reason, remember, problem solve, focus, and pay attention. It also can affect language, vision, behavior, and emotions.<sup>2</sup>

Various disorders can cause dementia, but Alzheimer's disease is the most common and

### **A Common Issue**

- 42 percent of residents in assisted living communities have some form of dementia.
- 61 percent of nursing home residents have moderate or severe cognitive impairment.
- 75 percent of people aged 80 or older who have Alzheimer's disease are admitted to nursing homes.<sup>1</sup>

accounts for 60-80 percent of dementia cases.<sup>3</sup> Because Alzheimer's is a progressive disease, dementia symptoms worsen over time, and they can manifest in different ways for different people. As a result of these complexities, a "one-size-fits-all" approach to caring for individuals who have dementia is not practical or advisable.<sup>4</sup>

Rather, senior care providers and staff members should strive to offer person-centered care — "a philosophy of care built around the needs of the individual and contingent upon knowing the person through an interpersonal relationship." This approach should consider each resident's symptoms, abilities, needs, and preferences.

Although the philosophy of person-centered care can seem expansive — and the reality of implementing this type of approach might seem daunting — senior care facilities can take strategic steps as part of everyday processes to work toward this goal. The following recommendations are intended to establish the foundation for offering person-centered care for residents who have dementia. Although this guidance is not all-inclusive, it provides fundamental considerations for senior care leaders, providers, and staff members.

### Learn as Much as Possible About New Residents

The concept of person-centered care hinges on understanding individuals beyond their diagnoses and symptoms and developing meaningful interpersonal relationships. The opportunity to establish this rapport begins during the admissions process for new residents.

Senior care providers and staff members should gather as much first-hand information as possible from new residents about medical and family history; current symptoms; anticipated needs; personal values, beliefs, and preferences; and

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relationships with family and people who play significant roles in residents' lives (significant others). This information can help the care team build a personal relationship with each resident, optimize the care planning process, and identify valuable ways to engage residents in their new surroundings.

Family and significant others also can provide important information about new residents. They might be able to offer insight about a resident's personal and medical history, functional capabilities, values, personal preferences, and behaviors. This information can be invaluable, particularly if a resident is already experiencing moderate or significant cognitive or communication issues. Further, because family and significant others likely know the resident better than anyone else, they might have vital information about potential triggers for dementia-associated behaviors as well as methods that have proven successful in helping the resident cope with these symptoms.

Unfortunately, in many cases, residents at senior care facilities do not have close family or significant others who can provide personal information. Residents who lack support networks

present a challenge for senior care providers and staff members who are trying to learn crucial details about each resident's life. In these cases, it might be helpful for senior care workers to do research about the time period and region in which the resident came of age. Although the information gathered from research will not be as personalized as what the resident, family, or significant other could provide, it can still lend important insight into the resident's life, values, and preferences.

As part of the information-gathering process, senior care workers should consider not only what information to obtain, but also how they obtain it. An article about person-centered assessment and care planning notes that "Personhood and relationship-based care align with assessment approaches that convey respect and seek to understand the subjective experience of the individual living with dementia." An approach that is engaging and respects the individual's preferences and beliefs helps establish the basis for personalized care and sets the appropriate tone for continued mutual respect and relationship-building.

### **Conduct Routine Monitoring and Assessment**

The needs and abilities of people who have dementia change over time, but this "progression is not always linear or predictable." Consequently, ongoing assessment and monitoring of residents who have dementia is essential for providing a person-centered approach to care.

The Alzheimer's Association advocates for comprehensive assessments by a multidisciplinary team every 6 months and interim assessments as needed to help prioritize each resident's needs and identify new or worsening symptoms. The *Alzheimer's Association Dementia Care Practice Recommendations* note that "Frequency of assessment in residential long-term care is guided by regulation, including key times such as: upon admission, after return from a hospital stay, and with significant changes in condition, function or behavior."

### **Initial Assessments**

Senior care facilities should implement a consistent monitoring method for newly admitted residents who have dementia. Adjusting to new surroundings, people, and routines can be disorienting in general, so initial assessment of new residents' behaviors might not adequately reflect their full cognitive and functional capabilities.

A monitoring protocol that occurs over an adjustment period (e.g., several weeks) and assesses factors such as daily functioning, cognition, comorbidities, behavioral issues, medication management, and personal relationships can offer more information about each resident's true needs and capabilities.<sup>10</sup>

### **Routine Assessments**

Routine assessments for residents are an opportunity to evaluate each individual's condition using reliable, valid tools to measure cognition, behavior, and function. The Alzheimer's Association identifies six areas that are essential components of assessment:

- 1. Cognitive status
- 2. Functional abilities
- 3. Behavioral symptoms
- 4. Medical status
- 5. Living environment
- 6. Safety

Research studies also have recommended assessing pain and using indicators for abuse or neglect.<sup>11</sup>

Although collecting and documenting objective information about a resident's condition is imperative, assessments also are an opportunity to understand more about the individual's

subjective experience and to continue forging a personal relationship with the resident and any family/significant others. "In a person-centered context, assessment begins with valuing the experience of being present with another human being, trying to understand that person's

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experience, and coming to know the uniqueness of the person."<sup>12</sup> From this perspective, assessments provide a path to learning and understanding the characteristics, personal values, and relationships that define the individual.

Information obtained over the course of routine assessments can help shape future interactions and decisions, which can improve the quality of personalized care as the resident becomes less autonomous and requires more assistance.

### **Educate Providers and Staff**

Providing person-centered care for senior care residents who have dementia is possible only if providers and staff members have the necessary competencies and opportunities to translate their knowledge into practice. The basis of establishing a competent workforce involves strong leadership support for a culture of learning, sharing, and empathy.

Senior care leaders should advocate for and support comprehensive programs that educate providers and staff members about dementia; its causes; the ways in which it might progress; associated physical, behavioral, and psychological symptoms; the perceptions and experiences of people who have dementia; and the principles of, and strategies for delivering, personcentered care.

Additionally, because posttraumatic stress disorder (PTSD) is common in the aging population — and individuals who have PTSD are more likely to develop dementia 13 — education also should help build a trauma-informed culture. Organizations that have trauma-informed cultures acknowledge the impact of trauma, recognize its signs and symptoms, respond with trauma-informed policies and procedures, and resist practices that can retraumatize individuals. 14

Training and education related to dementia and trauma-informed care should be part of orientation and ongoing in-service trainings.

These trainings should encourage provider and

# The Six Key Principles of a Trauma-Informed Approach

- 1. Safety
- 2. Trustworthiness and transparency
- 3. Peer support
- 4. Collaboration and mutuality
- 5. Empowerment, voice, and choice
- 6. Cultural, historical, and gender issues

To learn more, see *SAMHSA's Concept* of *Trauma and Guidance for a Trauma-Informed Approach*.

staff collaboration across departments and disciplines to reinforce teamwork and consistency in the provision of care. Training also should include a review of systems and techniques for sharing person-centered information about residents, such as values, beliefs, hobbies, personal preferences, and more.<sup>15</sup>

A well-educated and knowledgeable staff can "help build strong relationships and trust between care providers and individuals living with dementia." <sup>16</sup> In many instances, residents and their families/significant others will look to senior care providers and staff members for current information and guidance about Alzheimer's disease and dementia symptoms.

Other times, providers or staff members might be the first to notice early signs of dementia in a resident. Although qualified medical professionals should always diagnose and treat Alzheimer's disease and dementia, properly educated senior care providers and staff members can:

- Help direct residents and their families/significant others to appropriate resources
- Encourage residents to follow through with medical appointments
- Help reduce fear and stigma associated with dementia
- Facilitate meaningful discussions about residents' goals, wishes, and expectations

Providing competent, person-centered care for residents who have dementia requires dedication, motivation, and meaningful effort as well as a stable workforce that is not vulnerable to high turnover. Thus, in addition to advocating for and encouraging a learning environment, senior care leaders also must consider how best to support providers and staff members through adequate resources, flexibility, autonomy, recognition, and career development opportunities. "High performing leaders know that staff are the foundation of success, and when staff are valued, recognized, and feel served themselves, they in turn will more likely value and serve others." 17

# **Emphasize the Concept of Self-Hood**

At the core of person-centered care is the tenet of self-hood — the qualities, values, beliefs, and ideas that establish individuality. High-quality, personalized care for residents who have dementia puts a strong emphasis on self-hood and empowering residents to have meaningful relationships and experiences.

Senior care providers and staff members who strive to provide exemplary care should understand that the concept of self-hood persists even as a resident's cognition and memory

decline. In fact, "Researchers have found intact manifestations of selfhood in spite of significant cognitive impairments . . . it is not intact autobiographical memory that constitutes self or personal identity." <sup>18</sup>

Senior care facilities can lay the groundwork for focusing on self-hood with the collection of detailed medical and personal information about residents (during admission, as part of assessments, and within the framework of ongoing care and interactions). Yet, merely collecting information — and sharing as appropriate — does not equate to person-centered care. Senior care leaders, providers, and staff members must find ways to use the information to develop a personalized approach to communicating with residents.

The crux of a personalized communication strategy is understanding residents' perspectives and actions and accepting their realities rather than trying to reshape them. The Alzheimer's

Association explains that doing so "recognizes behavior as a form of communication, thereby promoting effective and empathetic communication that validates feelings and connects with the individual in his/her reality." <sup>19</sup>

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Senior care providers and staff members should attempt to gain a thorough understanding of residents' lives prior to their Alzheimer's and/or dementia diagnoses as well as the physical, emotional, and behavioral outcomes following diagnosis. This knowledge can help emphasize the concept of identity and foster compassion and empathy for each individual's experience.

When attempting to connect with residents in a personalized, compassionate, and empathetic manner, providers and staff members also should be careful to avoid communicating in ways that can actually depersonalize these encounters. Examples of depersonalization include talking to or treating residents as if they are children; labeling dementia symptoms in a negative manner (e.g., "disruptive," "angry," or "inappropriate"), which can result in improper treatment and medication management;<sup>20</sup> objectifying residents because of their disease or symptoms; and treating residents as if they are not present or cannot understand.<sup>21</sup>

# **Focus on Ways to Empower Residents**

Empowering residents who have dementia to participate in daily decision-making, take an active role in care planning, and engage in meaningful and fulfilling activities is another important area of focus for person-centered care. However, as noted earlier, dementia progression is not linear or foreseeable.

Dementia symptoms and experiences will vary from person to person and over the course of time for each individual. For instance, a resident in an early stage of Alzheimer's disease might be mostly independent, able to actively participate in care planning, and capable of performing most activities of daily living (ADLs). Over months or years, those abilities will decline — what once were everyday tasks might require more effort and could potentially be harmful in the absence of adequate assistance.

Because of the uncertain progression of Alzheimer's and dementia, it is incumbent on senior care providers and staff members to work with residents and their families/significant others to

determine each resident's physical and cognitive capabilities and to balance the desire for independence with the need for safety.

When a resident is in an early stage of Alzheimer's disease or has early symptoms of dementia, providers and staff members should directly ask the resident about the type of assistance required or desired, and seek "It is incumbent on senior care providers and staff members to work with residents and their significant others to determine each resident's physical and cognitive capabilities and to balance the desire for independence with the need for safety."

feedback about care experiences. "This can be empowering for the individual living with dementia as it allows him/her to have a say in the type of support he/she wants to perform activities of daily living like bathing, dressing or eating."<sup>22</sup>

Even as residents who have dementia become less autonomous, senior care providers and staff members can still find ways to empower these individuals. Examples include:

 Relying on nonverbal cues and behavior — such as facial expressions, gestures, or behavioral and psychological symptoms — to help determine residents' needs and preferences.

- Allowing residents to have personal items, such as photos, blankets, pillows, plants, small pieces of furniture, and other items that have sentimental value. These personal touches can help create a comforting environment for residents who have dementia.
- Avoiding unnecessary restrictions, such as limiting residents' ability to perform ADLs for
  which they are physically and cognitively capable of doing. Although each individual's
  abilities will change over time, senior care workers should help maximize independence
  and allow "as much autonomy as possible, as opposed to automatically assuming that
  the resident is incapable of participating in any treatment planning or decision-making."<sup>23</sup>
- Providing choices that emphasize shared decision-making and active engagement, such
  as asking residents to set their own sleep/wake schedules and make choices related to
  clothing, food, and activity options. Offering options helps residents feel a level of control
  in their daily living and helps providers and staff combat notions of infantilism.
- Offering activities that are designed to satisfy a variety of interests and a range of
  cognitive and physical ability levels. Meaningful activities can improve quality of life for
  senior care residents, reinforce independence, and help promote positive self-image. For
  residents who have dementia, "Attention to individual interests and functional
  competencies in selecting activities is critical to increasing participation and positive
  experience."24
- Encouraging social engagement among residents. Healthy interactions with other human beings are a vital component of sound mental well-being for everyone, not just people who have dementia. However, individuals who suffer from dementia are at risk of feeling disconnected because of their diagnoses and symptoms.<sup>25</sup> Offering these residents opportunities to socialize with other individuals who have similar interests (e.g., gardening, music, painting, or dancing) or to share experiences with other people who are coping with dementia can foster feelings of acceptance, understanding, and engagement.
- Recognizing special events and accomplishments. Although a diagnosis of Alzheimer's
  disease and the effects of dementia are life-changing, person-centered care techniques
  should emphasize that individuals can still have fulfilling experiences and meaningful
  relationships. Recognition of special events and individual accomplishments can

reinforce positive feelings of self-hood and value and provide additional opportunities for social engagement.

In addition to finding ways to empower residents who have dementia, senior care providers and staff members also should be vigilant in monitoring and routinely assessing residents to determine new needs that arise and to find ways to balance autonomy and safety. Providers and staff also should work closely with residents and their families/significant others — as well as with other health professionals (e.g., physical, occupational, and speech therapists) — to determine optimal care approaches that promote safe independence.

## **Improve Care Coordination**

Coordinating care is problematic across the healthcare spectrum because of the abundance of information, complex technologies, and competing priorities. Unfortunately, even small lapses in communication and information sharing can lead to significant errors and patient harm. For senior care residents who have dementia, the need for coordinated care is even more critical due to the unpredictability of symptoms, possible communication barriers, common comorbidities related to aging and dementia, and the number of healthcare providers involved in their care.<sup>26</sup>

To address these issues, senior care leaders, providers, and staff members must work to overcome obstacles to care coordination. A first step is to review policies related to documentation requirements and assess systems for information sharing. Without accurate, current, and consistent information or reliable systems, care coordination processes can easily break down or falter.

Senior care workers also should collaborate with residents' physicians and other healthcare providers to ensure all parties understand residents' treatment goals and care plans as well as individual roles and responsibilities.

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Additionally, being well-versed in interventions

used to treat dementia (pharmacologic and nonpharmacologic) can help senior care workers better understand the syndrome and treatment strategies, and they can encourage residents and their families/significant others to have meaningful discussions about symptom management with their physicians and other medical providers.<sup>27</sup>

Another important step in care coordination is educating residents and their families/significant others about, and preparing them for, common care transitions. The *Alzheimer's Association Dementia Care Practice Recommendations* explain that "it is important to understand [residents' and families'] need for information about common transitions, including across care settings, such as home to hospital or skilled nursing facility, nursing home to emergency department; within care settings, such as from an emergency department to an intensive care unit; or from one team of clinicians or care providers to another." Education and preparation can help facilitate the transition process and ease concerns about the unknown.

Transitions of care, or "handoffs," also require well-defined processes between facilities (e.g., senior care facilities and hospitals) or within a facility (e.g., across different units or care providers). Facilities should develop policies and procedures for transferring critical information, such as medical records, advance directives, medication information, and recent changes in condition.<sup>29</sup>

Handoff policies also should establish expectations for written and verbal communication among care providers and the use of appropriate tools, forms, and checklists. "Every member of the health care team must be accountable and responsive to ensure the timely and appropriate transfer of responsibility to the next level or setting of care." Senior care leaders should routinely audit care transition processes to ensure adherence and identify potential areas for improvement.

Finally, the focus on person-centered care should not be lost during care transitions. Transitions present an opportunity to revisit and share information regarding the resident's preferences and treatment goals. Providers and staff members should directly seek residents' input during transitions if the residents are able to participate, or they should consult with others who can advocate for residents

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and convey their wishes. When significant transitions of care occur, it is imperative for providers and staff to reevaluate health needs, reassess safety, and revisit goals of care.<sup>31</sup>

# **In Summary**

Dementia is a complex syndrome that presents multiple challenges for care providers, including individuals working in senior care and long-term care facilities. Residents who have dementia can benefit from personalized approaches that focus on treating them with dignity, respecting their personal values and preferences, and balancing safety and independence.

Senior care facilities can support person-centered care through strong leadership advocacy, ample opportunities for provider and staff education related to dementia care, strategies that focus on the importance of residents' self-hood and identity, a culture that promotes empathy, and ongoing quality improvement efforts focused on communication and care coordination.

# **Endnotes**

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