

ASSISTED
LIVING
PROVIDER
RESOURCE

CRUCIAL CONVERSATIONS

D E M E N T I A C A R E



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NATIONAL CENTER FOR ASSISTED LIVING



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INTRODUCTION

Dementia care is a priority for all long term care providers, including assisted living communities (ALC). In 2023, an estimated 6.7 billion Americans were living with Alzheimer's disease, and the Centers for Disease Control and Prevention predicts that number will nearly triple to 14 billion by 2060 as a result of the aging American population. With the growing number of Alzheimer's and dementia care diagnoses predicted, it is crucial to understand the value of and how to have conversations with residents and families about dementia, its progression, and how you are best able to help those who suffer from the disease. Dementia and cognitive impairment diagnoses can be frightening, intimidating, and daunting - especially since there are so many unknowns for both residents and families. Having a plan in place on how to start the conversation is key to ensuring the best possible outcomes for the resident and their loved ones.

STARTING THE CONVERSATION ABOUT DEMENTIA

Beginning to talk about dementia can mean difficult conversations. Emotions are running high for both the residents and their family members. But keep in mind that both you, your organization, and your staff want to ensure that they are best prepared to care for and interact with the resident experiencing dementia to the best of their ability. Navigating how to have an honest and informed conversation about dementia with residents and families is a critical part of being able to provide care and services. Try to keep it light and easy while asking simple and easy to understand questions.

SETTING THE STAGE

Residents and families may be uncomfortable, so it's imperative they share their thoughts and feelings as part of this crucial conversation. Stress, fears, uncertainties, and worries are running rampant. Families and residents are looking for concrete answers, which we do not always have. For example, how long will the type of dementia last, how long are the different stages, etc. Explaining that each person is unique to the dementia diagnosis and that they will progress at their own pace is important. It is for these reasons that setting the stage for this conversation, and similar conversations, is so vital.

Here are 10 suggestions on how to help you navigate these important discussions:

- 1. Choose the right people, time, and place.** Consider a time when things are peaceful and quiet, and the resident is well rested. Steer clear of high-stress events, loud noises, or other distractions. Try to aim for a cozy space that is comfortable and calming. Invite the right people and family champions to the discussion.
- 2. Start with understanding, empathy, and compassion.** This is a tough situation, and it is important that we recognize and empathize with what they are going through. Consider using statements such as "This is a tough time," "I imagine this is a lot for you," or "I would like to understand what you are feeling." These examples invite sincere discussions and show empathy.

- 3. Gather information.** There are various stages of dementia that differ greatly. These stages can also depend on the type of dementia or cognitive impairment diagnosis. Learn about the diagnosis before you sit down with the residents and their loved ones. Understanding the resident's specific diagnosis can help answer resident and/or family member questions.
- 4. Use open-ended questions.** Open-ended questions allow residents and family members to share their feelings and ideas. An example of an open-ended question might be, "Can you share your thoughts on your future care and living arrangements?" or "What are your thoughts on what you would like your care to look like?" Starting the conversation in this way lets the family set the stage and tone while you can adjust your statements to fit. This will allow the family to feel included, understand, and more likely to be willing to follow where you are trying to lead.
- 5. Validate their concerns and actively listen.** Pay attention to what is being said, respect their worries, and provide a safe environment for conversation while acknowledging their feelings. Help them feel safe and heard.
- 6. Involve others as needed.** Working together helps to create a more robust and comprehensive care plan that considers the residents' individual needs, wants, wishes, choices, and desires. Include those who know the resident the best if the resident is unable to fully participate. While this may not be a clinical scenario, most often having a site nurse present does help the message be better received by the resident and family. Another example would be to include a therapist if they were working with one. If the therapist is unavailable, ask them to provide input for the meeting that the staff can then share with the resident/family.
- 7. Be respectful, empathetic, compassionate, and patient.** This is a confusing and uncertain time for the residents and their family members. Slower understanding, processing speeds, and memory loss are distinct effects of dementia and can impact how quickly a resident is able to understand and comprehend the questions being asked and the conversation. Talk slowly, clearly, and use plain language to best facilitate an open, honest conversation. Short and simple sentences that allow time for the individual to process what was said are critical.
- 8. Make ample time for the conversation so nobody needs to 'run' anywhere.** To the resident and family, having 'all the time in the world' to discuss the complex issues means the world to them.
- 9. In the most simplistic way, focus on the resident and their needs** and then meet your resident and family where they are 'at' and bring them to where they need to be for the best resident outcome.

10. Consider holding a two-step meeting to reduce the stress on the resident. Step one would be to meet with family and listen to their concerns and questions for the future. This could be a more complex discussion with more information provided. The second step would be to meet with the family members plus the resident to allow for input from the resident. This second step should be simpler to identify what the residents' wishes are and discuss any helpful resources. Too much information can overwhelm and create frustration for the resident living with dementia.

Opening language that can be used to help the resident and their family, understand the purpose of the conversation may include:

“Our conversation today will help us provide the best care and services to you and your loved one. We want to ensure you have the best possible support needed to make the best decisions for your future. We want to gain a better understanding of your current preferences for your care and to better help your family understand your choices for the future if there comes a time when you can no longer communicate your desires.”

“We want to talk with you both (all) about how we can help provide the care and services you need and want. We are here to support you and help you make an informed decision when decisions must be made. For now, we want to get a better understanding of how best to provide this support, your preferences for care, and how to navigate if you (resident) are no longer able to communicate your needs and desires. Understanding your history, what is important to you, what you like and don't like will be so important to how we help. Also (family) we want to make sure that we are listening to you and your experiences.”

What can the resident and their loved ones 'expect'? Dementia progression varies from person to person. Let's review what some possible scenarios *can* be and then discuss how we can work together to mitigate any concerns:

Dementia disease progression, or sometimes referred to as advanced dementia, is a term used to describe the final stages of dementia. Advanced dementia symptoms typically include profound memory loss, such as not being able to recognize close family members as they once did; speech deficits or complete loss of coherent speech also known as aphasia; total functional dependence and loss of bowel, bladder function, and ability to ambulate. Think about this as the muscles in the body slowly stop communicating with the brain. One of the most common medical complications is problems with eating, and sometimes vision range challenges may inhibit physical abilities, which can impact chewing, drinking, and swallowing. The next most common medical complication is infections. For example, food can go down the windpipe (muscles are not communicating that the flap should cover the windpipe) to the lungs which can lead to what is called aspiration pneumonia. Over 90% of residents with dementia will have difficulty with food and swallowing. Nearly 50% of residents with advanced dementia will experience infections and fever. As a terminal illness, residents with advanced dementia commonly die due to the complications caused by the disease process, such as pneumonia.

Here is an example of language that can be used in those discussions with the family.

“It is my understanding that you have known about the dementia diagnosis for a while now, and your loved one is now at a stage that they need extra support. Unfortunately, dementia doesn’t only affect the brain, but it also impacts the body. As you know, your loved one is having more difficulty with moving around, eating, and is requiring more help and support from the team and is dependent on others for care.”

Depending on whether your assisted living community can provide advanced care and services, you may need to consider addressing palliative and hospice care or the concept of moving the resident to a higher-level nursing care facility. Palliative care and hospice services do not replace the care received in your assisted living community but rather enhances the quality of care. This concept can be confusing for families, as they may think that palliative and/or hospice care will replace the care received in your assisted living community. Palliative care is specialized medical care focused on improving the quality of life of people facing serious illness. This partnership of the person, medical specialists, and family is appropriate from the time of diagnosis and can be provided along with curative treatment. Palliative care is holistic and supports the person and family, not only by controlling symptoms, but also by helping understand treatment options and goals. Hospice is a model of care, focused on providing comfort, relieving symptoms, and offering support for people with a life expectancy of six months or less and their family. Hospice involves an interdisciplinary approach to provide medical care, emotional, social, and spiritual support.

These conversations should be held with the residents’ best interests at the heart of the discussion. You know your residents very well, show the family how your suggested approach ‘fits’ your resident both historically and in the future. Consider having resources or contact information for support services available at the meeting or offer to assist in making calls to set up interview opportunities with support service companies. This is also a good opportunity to remind the family of the limitations in care based on the scope of care provided within your community (i.e., ability of services such as feeding assistance).

It is important to remember that moving a resident to a higher level of care is an extremely stressful decision for the family and a significant change for the resident. The family may feel like they are “letting mom/dad down”, or if it is a spouse they may feel like a failure for not being able to care for their partner. During the discussion, focus on the fact that ‘we want the resident to be safe in the environment’ and when the resident is not safe changes need to be made. As staff, you may need to step in and shoulder the blame rather than putting the burden on the family members who are likely already feeling it to have the discussion with the resident. This heavy discussion with the family can be made better by keeping the focus on what is best for the resident.

ALLEVIATING FEAR AND UNCERTAINTY

Along with a dementia diagnosis comes a plethora of fear and uncertainty. There is the fear of the unknown, fear of the disease progress, fear of losing one's memory or ability to recognize family members, and the uncertainty of how the disease will impact the residents' life. These fears and uncertainties need to be addressed and reduced as much as possible for residents to have the best quality of life while in your care. Discuss fears expressed by the resident and their family members first, if any. Then proceed to discuss other fears they may not have communicated, but may have, as outlined below (and as they fit the resident's personal progression). Follow each fear with how the assisted living community's actions help mitigate fears and concerns.

Person-centered care is a relationship based and focused on meeting the resident's needs. While person-centered care is used frequently within the profession, residents and families are always new to the term. Decision-making is directed by the resident (or with the assistance from family or a designated surrogate decision maker if the resident is unable to fully communicate). Explain simply and address how you can meet the residents' needs and preferences.

One fear that residents and families have is that they will lose their ability to make their needs known. This is where person-centered care can help alleviate this concern for residents and their loved ones. Person-centered care is focused on meeting the individual resident's needs where they are at in any given stage.

Ways to accomplish person-centered care may include:

- Focusing on the resident and providing care that is guided and informed by their goals, preferences, and values, a holistic shift from tasks and care;
- Promoting and supporting each resident's sense of purpose and what is meaningful to them;
- Encouraging personal development of residents on an individual basis that supports the resident's goals;
- Maximizing the resident's dignity, respect, autonomy, and choice (example: "do you prefer this shirt or this one?"), privacy, socialization, independence, preferences, and safety (example: "let's get you into some dry clothes" versus "let's get you cleaned up");
- Supporting lifestyles that promote, empower, and enable mental and physical health and fitness;
- Promoting family and community involvement;
- Developing positive and meaningful relationships among residents, staff, families, and the community; and,
- Ensuring the dining experience is person-centered.

Another fear for residents and their loved ones is that the community and staff will not really know the resident well enough to be able to anticipate and meet their needs. Evaluations of any prospective resident and current residents are critical in understanding the individual resident's wants, needs, desires, likes and dislikes, hopes, fears, and past history. Preparing residents and families to also know that residents can and do change and their preferences as they move through the progression of dementia. This may not be expected based on personal history, and our staff will adhere to resident requests if/when communicated regardless.

If your community offers more than one service line, such as independent living, assisted living, skilled care, and memory care, consider collecting resident wishes and desires for each step of the way. Collecting information along the way allows the resident to participate from the beginning. With this information your team will have the opportunity to understand the individual resident's wants, needs, desires, hopes, fears, and history.

Global elements of evaluations may include:

- Details about the person's medical and life history;
- Current diagnoses, physical abilities and limitations, determining what they are able to do on their own, and what level of assistance is needed with which tasks;
- Cognitive patterns, mood, and behavior, such as are mornings better or afternoons and plan your evaluation with that in mind while including times throughout the day so you get an understanding of how the person does throughout the course of the day and night;
- Cultural patterns in the individual's life, while also taking into consideration hobbies and activities that the resident enjoyed that can be adapted for them now;
- History of trauma;
- Barriers to communication (verbal and non-verbal, visual and auditory deficits and impairments) or thinking, while considering alternative means of asking questions, such as using yes/no questions instead of open-ended questions for residents with aphasia;
- What gives the resident purpose or makes them feel purposeful;
- Promote lifelong learning activities;
- Status of and preferences for personal grooming, bathing/showering and time of day, and activities of daily living (ADLs); and,
- Their preferences for social situations such as recreational activities, spiritual needs, or physical activity.

The fear of pain, depression, loss of social engagement, and the ability to eat can all create uncertainty and fear for both residents and family members. Here are some strategies to help address these fears.

Addressing fears of pain, depression, loss of social engagement, and the inability to eat include:

- **Pain evaluation and management.** Pain is not normal, often under or untreated, and may be a cause of behavioral expressions. Evaluate pain initially and on an ongoing basis for residents who have dementia. Observe the resident for physical signs of pain, such as grimacing, moaning, sighing, slow movement, or withdrawal of extremities during care. You may want to consider using a pain scale that is appropriate for the resident (i.e., 1-10, face scale, color scale, etc.). Once pain is determined, management of the pain can begin. Pain management may include pharmacological medication interventions, as well as non-pharmacological interventions such as exercise, massage, talk therapy, aroma therapy, music therapy, pet therapy, compassionate touch, relaxation therapy, and chiropractic alternatives.
- **Depression evaluation and management.** Cognitive impairments and dementia can add a challenge to coping with changes and this may lead to depression. Engaging residents in formalized programs, activities, social events, and encouraging them to interact with others can help reduce depression symptoms. In some situations, the inclusion of a mental health care provider may be needed to help further support the resident.
- **Loss of social engagement.** A comprehensive evaluation and person-centered approach to care is important in understanding the resident's social history, life story (including occupations, education, hobbies, etc.) and identifying their challenges, strengths, preferences, cultural values, history of trauma, and interests. By knowing this information, staff are better able to tailor programs to meet the residents' unique and individual needs.
- **Inability to eat.** Changes in cognition related to the advanced stages of dementia can create the challenge of being able to feed oneself. As dementia advances, providing finger foods may be more effective than foods that require fine motor skills of cutting and using silverware. Finger foods also help the resident maintain their dignity during the social dining experience.

Safety is another fear that can be challenging to address. Safety can be impacted by a number of things such as vision changes, falls, wandering, exit-seeking, or past instances of elopement. Families need to be reassured that you understand the value of safety and will do as much as you can to help keep their loved one safe. However, it is also important to not make promises that you may not be able to keep.

Addressing safety concerns and fears may include:

- **Elopement or exit-seeking is a concern for residents with dementia.** Understanding the nature of wandering behavior helps staff, family, and caregivers understand the need to wander and appropriately intervene, such as are they thirsty, hungry, or need to use the bathroom. You should look for patterns in wandering, such as a certain time of the day - including during shift

change, after family visits, or when family doesn't visit. Structured wandering opportunities, such as enclosed wandering paths or wandering paths in secure outside spaces as the weather allows, may decrease the desire to leave communities unsupervised. Additionally, knowing the resident and understanding what they might be looking for while wandering can help to address anxiety of not finding what they need (i.e., need to go to work, finding a family member, etc.).

- **Evaluate residents with dementia initially and ongoing triggers leading to exit-seeking behavior.** Consider using an [Elopement Risk Assessment](#). This can help in developing the person-centered service plan that promotes choice, mobility, and safety as mechanisms to manage elopement behaviors.
- **Do not make promises that you may not be able to keep.** Empty promises such as, "We will keep your loved one safe by ensuring that they have no falls," are impossible to keep, can set your community up for failure, and are a liability risk. Acknowledge that you and your team will do everything you can to reduce falls from happening, but you cannot prevent or guarantee that a fall won't eventually happen. Having open, honest conversations about safety is a fundamental discussion that can help pave the way for further conversations in the future.
- **Advise the family and responsible party along the way of the limitations and services included at the level of care your community is licensed to provide.** Having clear communication of what your community can and cannot provide is very important and reduces the likelihood of unmet expectations.

COORDINATION OF CARE

To ensure the holistic wellness for the resident, coordination of care between providers is essential. Strong vendor partners for this may include primary care, therapy, behavioral health, pharmacy for routine medication reviews, etc. The coordination of providers may provide additional peace of mind for everyone.

WRAPPING UP THE CRUCIAL CONVERSATION

Consider distribution of support group information for family members (if available in your area) and disease progression website links for reinforcement of family education. Reiterate the importance of self-care for every person present. Please emphasize that ongoing communication is key to the resident's success in this disease progression. Distribute, again, your assisted living community contact information to ensure everyone has it. Discuss if scheduled calls, emails, texts or meetings are needed at this time. If not, please note that those options are always available if minds change. Reiterate the next steps that will be taken and thank them for their time and involvement in care planning for the resident. Last, do the follow up as you said you would. This ensures the relationships remain strong and solidifies that foundation the resident requires for success.

Having a one-page letter the families can take along may be beneficial. Site contact information, suitable dementia information links for reference, etc. There is a lot of information that is discussed and sometimes having something to refer to later is helpful for families.

EDUCATION, TRAINING, AND SUPPORT SERVICES

- In some instances, residents may move into the community without any cognitive issues. However, afterwards (i.e., six months or a year later) cognitive issues including short term memory, dementia, Alzheimer's, etc. may begin to surface. The right diagnosis or 'need for diagnosis' is important to better serve the resident but may not always be a shared goal with or within the family. Open conversations with the family and education on symptoms of the different types of dementia can be helpful.
- Educate families on the services your community provides, including memory care and the benefits of memory care services including the safety aspects of memory care. Early education on benefits of memory care and your ability to provide services can help reduce the risk of elopement and can help family members understand the importance of memory care services while also reducing the community risk of liability.
- Educate your staff on the different dementia diagnoses. Alzheimer's is a type of dementia, but not all dementia is Alzheimer's. For this reason, it is important to educate staff on the types of dementia related to your resident population. This can also support person-centered care by knowing and understanding the type of dementia that each resident is experiencing.
- Assist families in finding support groups and learning opportunities.
- Ensure that your resident contact information is accurate and up to date. Some residents may be able to make independent decisions whereas others may have a family member or designated surrogate listed to make decisions on their behalf. Not all residents want their family members involved or even a particular family member involved. Knowing the correct contact information for the resident is key.
- There may be times when residents develop 'new friendships,' they may 'hold hands' with another resident, or they may engage in 'sexual encounters' with others. Families should be educated before this occurs so as to not be surprised or horrified to find out that 'mom has a boyfriend' or they are wandering into other's apartments, etc.
- Families should be educated about falls even if the resident has no history of falls. Falls may happen for any number of reasons, and it is important that families understand and what they can do to help reduce the risk of falls.
- As a community, it is important that you always operate within the confines of your licensure and lease agreements. Sometimes this can be hard because you want to do what is best for your residents.

CONCLUSION

Caring for people with the various types of dementia is a privilege. Providing a safe home with opportunities for engagement and successful living should be the top priority for all caregivers in assisted living settings. Utilizing tools such as the initial and ongoing evaluations and conversations, person-centered approaches, and social engagement programming can increase the quality of life for residents with dementia and improve their level of satisfaction and well-being. It is important to try to update the resident's family as much as possible, and if you can do it in writing, that helps you keep track via documentation while also giving the family a window into their loved one's daily life. They have entrusted their loved one into your community's care and they want to know how things are going, including both good and bad.

NOTE: *The assisted living profession continues to grow and evolve as does NCAL's perspectives on our changing profession. The concepts and terms used in this document may vary from state to state and are provided as a framework to help promote conversations and understanding dementia progress with residents and family members in assisted living. The ideas and content included in this document are not "standards of care" nor should be construed as such.*

RESOURCES

[Alzheimer's & Dementia | Alzheimer's Association](#)

[NCAL Guiding Principles for Dementia Care](#)

[Dementia Care Practice Recommendations | Alzheimer's Association](#). 2024

Person-Centered Assessment and Care Planning. <https://academic.oup.com/gerontologist/article-lookup/doi/10.1093/geront/gnx173>

The Fundamentals of Person-Centered Care for Individuals with Dementia. <https://academic.oup.com/gerontologist/article-lookup/doi/10.1093/geront/gnx122>

Evidence-Based Interventions for Transitions in Care for Individuals Living with Dementia. <https://academic.oup.com/gerontologist/article-lookup/doi/10.1093/geront/gnx152>

[The Alzheimer's and Dementia Care ECHO® Program | alz.org](#)

[Dementia Care Provider Roundtable | Alzheimer's Association](#)

[Elopement Risk Assessment](#). HealthCap Risk Management & Insurance. 2023. <https://healthcapusa.com>

[Dementia Care Connect Community](#)

[CARES® Delivers Dementia Care Training That's Real and Relatable](#)