



**A GUIDE TO QUALITY CARE
FROM THE PERSPECTIVES OF
PEOPLE LIVING WITH DEMENTIA**



A special thanks to the Alzheimer's Association® National Early-Stage Advisory Group, whose members continue to help us understand the lived experience of Alzheimer's and other dementias, and teach us how to better meet their needs throughout the disease course.

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Summary

With more than 5 million Americans living with Alzheimer’s disease, direct care workers — such as nurse’s aides, home health aides, personal and home care aides — provide most of the paid long-term care to older adults living at home or in residential settings. From the perspective of individuals living with dementia, quality care includes person-centered care techniques that address their unique experiences and needs, which is contrary to a “one-size-fits-all” approach.

In this guide, survey data and interviews from individuals living in the early stage of Alzheimer’s or with other dementias are used to describe quality dementia care, explore topic areas relative to the dementia experience and share approaches for care providers. As Alzheimer’s progresses, individuals living in the early stage will depend on care providers to help preserve their sense of identity, autonomy and quality of life with dementia. The information on the following pages provides valuable guidance for people living with the disease, their caregivers, other family members and anyone concerned about providing high quality dementia care.



Background

For more than a decade, the Alzheimer's Association® has committed itself to addressing the needs of individuals living in the early stage of Alzheimer's or with other dementias. In January 2006, the Association launched its Early-Stage Initiative and formed the National Early-Stage Advisory Group (ESAG). The group is comprised of individuals from across the United States living with early-stage Alzheimer's, other dementias or mild cognitive impairment (MCI) and includes individuals with younger-onset Alzheimer's, meaning they developed symptoms before age 65. "Early-Stage" refers to people, irrespective of age, who are diagnosed with Alzheimer's disease or related disorders and are in the beginning stage of their disease.

Advisors are an invaluable resource to the Alzheimer's Association as they represent people living with the disease and bring a unique perspective to key efforts of the Association. Through their work as national spokespersons for the Association, advisors raise awareness of Alzheimer's disease and early-stage issues, reduce stigma, advocate to increase funding for Alzheimer's research, and provide input about programs and support services for people in the early stage of Alzheimer's or with other dementias.

Since the launch of the National Early-Stage Advisory Group, 132 individuals have participated in the program, fulfilling an average of 50 national engagements each year, including presentations to the Social Security Administration (SSA), Food and Drug Administration (FDA), Office of Minority Health and the Special Committee on Aging. As advocates and advisors, the group also provided input on the development of The American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia, and the American Academy of Neurology Patient and Provider Shared Decision-Making Tool. In addition, advisors have ensured that the perspective of those living with the disease was included in the Food and Drug Administration (FDA) Patient Representative Program and the National Alzheimer's Project Act (NAPA) Advisory Council on Alzheimer's Research, Care and Services.

In preparing this guide, the Early-Stage Initiative department of the Alzheimer's Association solicited questions from researchers assigned to conduct literature reviews and draft recommendations for each of the eight topic areas of the Alzheimer's Association 2018 Dementia Care Practice Recommendations. Questions were reviewed and modified as needed to ensure they would solicit responses that would help inform the authors. The survey consisted of 30 (mostly open-ended) questions shared through SurveyMonkey®, the online survey software.

A group of 43 current and former National Early-Stage Advisors received an email describing the Dementia Care Practice Recommendations Project. The email contained a link to the survey questionnaire and provided advisors the opportunity to revisit the survey over a period of seven days. A total of 22 surveys were completed for a response rate of 51 percent. A team from the Alzheimer's Association (Sam Fazio, Ph.D., director, Quality Care and Psychosocial Research; Monica Moreno, senior director, Care and Support; Emily Shubeck, associate director, Care and Support) summarized the survey data and recommendations.

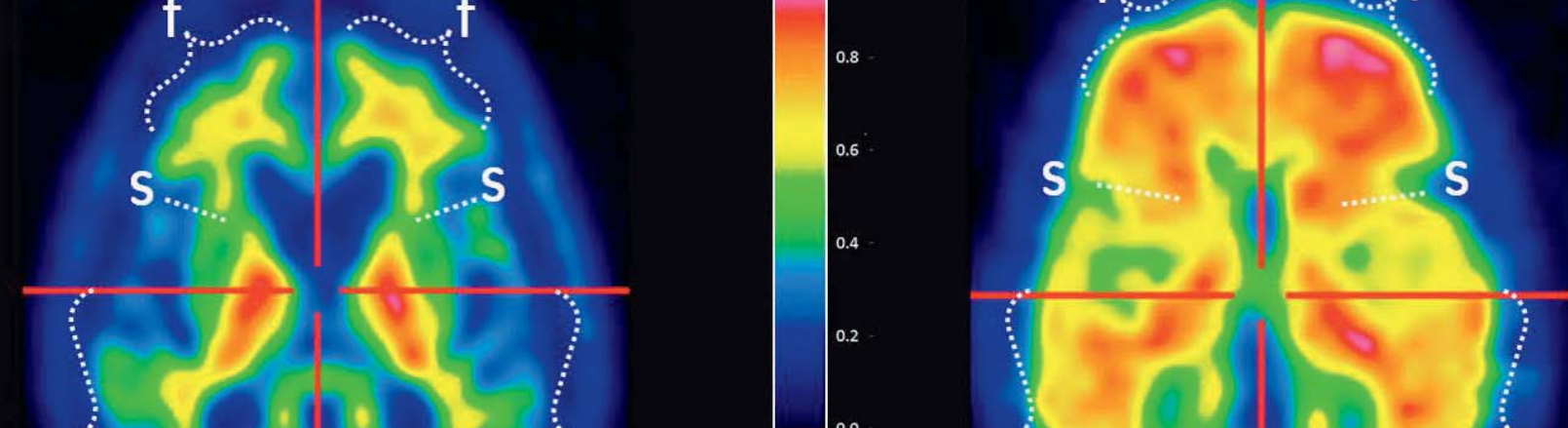


Themes in Quality Care

This guide synthesizes the feedback received from survey respondents, as well as additional information obtained from individuals living with dementia throughout the 10 years of the Alzheimer's Association Early-Stage Initiative. From this feedback, the following themes emerged as ways to provide quality care to people living with Alzheimer's or other dementias:

- » Encourage early detection and diagnosis.
- » Share appropriate information and education.
- » Get to know the person.
- » Maximize independence.
- » Practice patience and compassion.
- » Personalize care to meet individual needs and preferences.
- » Adjust care approaches to reflect day-to-day needs and abilities.
- » Provide ongoing opportunities for engagement that have meaning and purpose.
- » Ensure coordination among those who provide care.
- » Train staff on the most current disease information and practice strategies.
- » Inform and include the individual in new interventions as appropriate.
- » Create a safe and supportive environment that reflects the person's characteristics, personality and preferences.

These themes are consistent with the preferences for individualization and autonomy expressed by individuals living with early-stage Alzheimer's or other dementias through survey responses and the Association's ongoing dialogue with this group.



Encourage Early Detection and Diagnosis

Quality person-centered care for individuals living with Alzheimer’s and other dementias begins with early detection and diagnosis. Care providers can often be the first to observe changes in memory and thinking, sometimes even before family members. The nature of a care provider’s role offers the unique opportunity to observe changes in their own environment. These observations can become even more vital when an individual lives alone. In the early stage of Alzheimer’s many people continue to live successfully on their own, however, as Alzheimer’s progresses, the individual may lack insight into the changes occurring or may not be available to observe the day-to-day challenges and safety issues.

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The decision to see a doctor regarding memory and thinking problems was made primarily by the individual living in the early stage of Alzheimer’s after experiencing disruptive changes in memory and thinking that were affecting daily life. As one person reported, **“I went to see the doctor after witnessing terrible Alzheimer’s symptoms in my family, and after serious short term memory loss myself [including] inability to multi-task, which earlier I exceeded at.”** While many individuals recognized their symptoms before anyone else, having others share their observations and concerns was extremely important as it validated their suspicions and experiences. For some individuals, concern voiced by others is what encouraged them to visit their doctor.

Individuals living alone also stated the importance of hearing the concerns of others regarding their memory and thinking problems as validation for their own concerns. As described, “It was confirming. Helpful in that way as I wrestled with what the hell was going on.” The absence of a care partner to recognize these changes early on could have resulted in a delay in diagnosis which may have placed them at greater risk for safety issues such as wandering and self-neglect.

For many individuals who received a diagnosis of Alzheimer’s or another dementia, early detection and diagnosis validated their concerns and provided a sense of relief in knowing the cause of their symptoms. As one person stated, **“It validated there was something wrong, and I wasn’t going crazy.”** For others, an early diagnosis allowed them the opportunity to benefit from early intervention, which included education about dementia, support services, local resources and care planning. Another benefit was the ability to make decisions about issues that would affect their life including legal, financial and end-of-life planning. As one individual described, **“You are able to help plan your future and make the tough decisions so your family does not have to later.”**

An early diagnosis also provided opportunities to develop strategies for *living* with dementia. These included adopting a healthy lifestyle such as following a Mediterranean diet; staying socially, mentally and physically active; keeping a positive attitude in order to live a quality life with the disease; and, as one person stated, “a purposeful though changed life!”



Share Appropriate Information and Education

Receiving a diagnosis of Alzheimer's disease or another dementia is life-changing. It is not uncommon for people living in the early stage of Alzheimer's and their care partners to feel responsible for finding answers to the many questions a diagnosis creates. If diagnosed later in the progression, the individual with dementia is often unable to be an active participant in planning for the future and making decisions that will impact his/her life. Often, caregivers are left to assume the responsibility of finding information and resources, including what to expect and how to plan for the future, while at the same time trying to manage the demands of caregiving.

Market research conducted by the Alzheimer's Association found that most individuals in the early stage of Alzheimer's and their caregivers locate information about dementia through internet searches (BCG, 2015). For individuals with a diagnosis, as well as care partners/caregivers, the market research indicated that this process was overwhelming, confusing and the large number of available resources — combined with the lack of direction on the most trustworthy source — was frustrating (BCG, 2015).

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Individuals living in the early stage of Alzheimer's or with another dementia confirmed that there continues to be a lack of appropriate information and resources shared immediately following a diagnosis. Several individuals reported, "I read all that I could through online sources and other periodicals." They overwhelmingly agreed that access to appropriate information and education soon after diagnosis is an important component of person-centered care and learning to accept the diagnosis. This information was perceived as "very helpful in understanding the prognosis and what to expect as the disease progresses." Basic information about Alzheimer's and how to live a healthy life with dementia were identified as topics that would be most helpful post-diagnosis, and as explained by one individual, **"There is life after diagnosis and I have learned to live life to the fullest."**

People living with dementia frequently used education programs to obtain information about their diagnosis including prognosis, treatment and the impact on day-to-day life. The most common platform for receiving information was online. One individual stated, **"The education program I attended provided me with a blueprint of things that I would need to take care of,** from appointing a proxy to meeting with an elder-care attorney to formulate a plan." For many, support groups connected them with others living with dementia and provided a sense of comfort in knowing they were not alone. Many respondents benefited from ongoing counseling from care providers and physicians who helped manage the challenges and emotions that come with living with dementia.

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Get to Know the Person

One of the core components of person-centered care is getting to know the individual living with dementia. No two people living with Alzheimer's or other dementias experience the disease in the same way, so taking the time to learn about a person's life history and the qualities that make them unique can foster a more supportive relationship with care providers. As Alzheimer's progresses and the individual loses the ability to communicate, care providers will need to rely on the input of others to develop strategies that best meet the care needs and preferences of the individual living with dementia.

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According to individuals living with dementia, care providers should engage them in direct communication in order to understand who they are as a person. The best way to learn about the person with dementia is to listen and ask questions about his/her needs and expectations. As one person shared, "Spend time with me and inquire and discuss my past experiences, activities, likes and dislikes, goals, feelings, and desires," while another commented, **"Listen and speak to ME, the person living with dementia."**

Care providers should consider how individuals living with dementia perceive their new identity with the disease and as one person advised, "Find out all they can about me — my life previously, my family dynamics, who I am." In the early stage, persons living with Alzheimer's desire to share information that gives care providers a broader picture of their personhood. As one individual described, **"I want the opportunity to tell them something about myself that they wouldn't necessarily know ... my life, my hopes, my dreams."**

For those living in the early stage of Alzheimer's, the increasing loss of independence threatens their overall quality of life. As a result, they want to give care providers input regarding their current needs and preferences as Alzheimer's progresses. As one person commented, "The interventions that I now resist may be the ones that I need to try later." They also want care providers to know that while some interventions may be successful for one individual, they may not be effective for another.

As Alzheimer's progresses, people in the early stage want care providers to seek input from family members and friends to gain a better understanding of their value system, history, preferences, personality traits and behaviors. As one person suggested, **"Make contact with persons who know me from their direct experience with me,** such as my adult children, siblings, friends and medical professionals who have worked with me." An understanding, inclusive and respectful approach to diversity was also seen as an important component in providing person-centered care. As described by one individual in the early stage, "Accept me as a person from the LGBT community."

One of the most compelling requests voiced by people with dementia was the hope that care providers would employ patience, especially as Alzheimer's progresses and the triggers that can cause behavioral and psychological symptoms of dementia (BPSD) maybe hard to identify. They want to be treated as care providers themselves would like to be treated. As one person stressed, **"We are people with feelings."**



Maximize Independence

Alzheimer's and other dementias are associated with the gradual loss of cognition and ability to perform the functions of everyday life. As a result, many individuals feel overwhelmed by the sense of loss surrounding their autonomy. One of the greatest challenges care partners face in the early stage of Alzheimer's is not knowing when and how much assistance to provide. For individuals who live alone, changes in the ability to independently perform activities of daily living will require the support of others to ensure their safety.

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People living in the early stage of Alzheimer's felt strongly about remaining independent for as long as possible. They see care providers as playing an important role in helping to maximize their independence, but want them to provide assistance "in the right ways." As one person stated, **"Let me do as much as I can [by myself] and help when I need it or get confused."**

Determining *how* care providers provide help was identified as critically important in helping those living with the disease maintain a sense of autonomy and control over their life. Individuals in the early stage reported that they need ongoing communication with care providers as Alzheimer's progresses to identify coping strategies that foster their independence. As reported by one individual, "Try different things to help me navigate the uncertainties that lie ahead." Knowing what type of assistance is needed and how the individual wants to be helped are considered important factors in providing person-centered care. For example, one individual commented, **"Ask me HOW I want you to help me,"** while another stated, **"Ask me what I am comfortable doing on my own and what activities I think I need help with."**

“ Let me do as much as I can [by myself] and help when I need it or get confused. ”

“ Ask me what I am comfortable doing on my own and what activities I think I need help with. ”



Practice Patience and Compassion

Part of person-centered care includes engaging the person in dialogue about their experience living with dementia. This information can provide valuable insights on how dementia impacts emotions, thoughts, behavior and day-to-day functioning. Understanding the personal impact of Alzheimer's or another dementia on the individual receiving care may inspire care providers to practice patience and compassion. As Alzheimer's progresses and the ability to communicate is affected, care providers will need to rely on patience and compassion to interpret the needs of the person and provide appropriate care.

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To gain a better understanding of the experience of living with Alzheimer's or another dementia, individuals living with dementia expect care providers to **“talk with me as well as to me.”** Finding creative ways to preserve the dignity of the person with dementia and make them feel valued were also identified as essential to providing person-centered care. Individuals felt strongly that care providers must be patient, caring, concerned and maintain a sense of humor. One person suggested, **“Know that my heart is the same as long as I am surrounded by LOVING attention.”**

When looking toward the future, individuals expressed deep appreciation for care providers and the role they will play as Alzheimer's disease progresses. Recognizing that the progression of Alzheimer's may make providing care challenging, one person wanted care providers to know, **“I will most likely be resistant to help. I ask for patience, understanding and forgiveness for those with whom I will battle. I would like them to know that I do appreciate their help and support.”**

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Personalize Care to Meet Individual Needs and Preferences

Personalized care requires an understanding of an individual's needs and preferences and should include input from the person living with Alzheimer's or another dementia. In the early stage of Alzheimer's, care providers can seek feedback directly from the individual. 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. In the later stage of Alzheimer's, preferences and needs may be expressed through other forms of communication, including facial expressions, gestures, or behavioral and psychological symptoms of dementia (BPSD) such as wandering, agitation or anxiety. Allowing for flexibility as Alzheimer's disease progresses is necessary as needs and preferences will continue to change, sometimes daily.

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Regardless of the environment, individuals living in the early stage of Alzheimer's conveyed that they would prefer to set their own schedules for activities such as meal, bath and bedtime. They stated that while some preferences might be "very important" to them today, they will likely change over time. As a result, care providers should be flexible and attempt different strategies to help them navigate the daily uncertainties. As one individual explained:

"I think one of the most important ways that care providers can personalize their approach is to be flexible. For example, now I am an early riser. That may change. I may prefer to have a later breakfast. Right now I love to take a hot shower every morning. That may change. I may prefer a soothing bath. Please pay attention as things change for me and be flexible."

As the ability to communicate becomes more difficult, people living with dementia want care providers to find new ways of identifying their needs and preferences. One person stated, **"I will not always be able to communicate my needs and so I ask you to be detectives to help figure out what is troubling me."**

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Adjust Care Approaches to Reflect Day-To-Day Needs and Abilities

As Alzheimer’s disease progresses, a person’s needs and abilities will change. Progression is not always linear or predictable, so for individuals living with dementia, a “one-size-fits-all” approach to address day-to-day needs does not reflect their individuality or current abilities. Rather than making assumptions about a person’s needs and abilities, care providers can help maximize independence by being flexible with approaches to activities of daily living. This type of flexibility is critical to individuals living with dementia who value a person-centered approach that doesn’t require a rigid application of intervention techniques.

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For individuals living in the early stage of Alzheimer’s, each day or hour may present a new challenge or opportunity to maximize independence. Respondents in the early stage do not want care providers to assume support or intervention is needed; they suggest spending time monitoring individual needs to determine the best and most appropriate opportunities to provide support. As an effective way to balance shifting needs and abilities, one responde requested “Consistent observance of my changing capacity, while helping me discover new ways to accomplish the activities that are important to me.”

If a specific technique is not working, individuals living with dementia recommended that care providers avoid forcing a solution. One respondent suggested, **“Allow me to complete as much of the activity as I can.”** This balance between maximizing independence and providing support is an essential component of living a quality life with dementia. A combination of patient reassurance and guidance was summarized as **“practice tolerance of my diminished capacity combined with gentle but persistent encouragement to be all that I can be.”** Individuals living in the early stage of Alzheimer’s have reported experiencing “good days and bad days.” They recommended that care providers take a flexible approach to daily care that promotes a sense of autonomy and control for the person living with dementia.

“**Allow me to complete as much of the activity as I can.**”

“**Practice tolerance of my diminished capacity combined with gentle but persistent encouragement to be all that I can be.**”



Provide Ongoing Opportunities for Engagement That Have Meaning and Purpose

For individuals in the early stage of Alzheimer's, one of the most vital aspects of living well includes an opportunity to stay connected and engaged with others. After they receive a diagnosis, people living with dementia may feel isolated or removed from their social networks. Connection to others living with dementia, social activities and community involvement can improve feelings of inclusion or acceptance and provide meaningful engagement.

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Flexible engagement options that meet changing needs and provide meaningful opportunities to connect are important to individuals living with dementia. As one person stated, "I want to interact with other residents in both structured and impromptu meetings." For others, the setting of the encounter is an important consideration. One individual suggested, **"Having comfortable places to communicate with others might help people to stay active."**

To promote engagement with others, individuals living in the early stage request "activities that are varied and available." For one person living with dementia, meaningful activities were those that encouraged "interacting with others and sharing ideas." While some prefer interactions that reflect their personality traits, care providers should be flexible to shifting preferences. As one person stated, **"I like interaction. I really enjoy being with people, so a very social environment would be good."** While another person acknowledged, "I love to sing and it might make me very happy to sing with old friends or in a group, but it might not."

Individuals living with dementia stated they prefer engagement opportunities that are personally meaningful and will provide connection to others. The value of peer support and "knowing I was not alone" was mentioned by many in the early stage as a critical component of social engagement. "Social interaction is so very important," one respondent noted. Care providers should consider opportunities that go beyond reminiscence. According to one respondent, **"This could be the best time of my life. I don't have to spend all my time just remembering my past."**

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Ensure Coordination Among Those Who Provide Care

An effective care team includes care providers working collaboratively to meet the unique and changing medical, social and emotional needs of the individual as Alzheimer’s disease progresses. Care team participants typically include medical professionals, community providers, friends, family and the individual living with dementia — all working together toward the goals outlined in the care plan.

It is critical to include the personal perspective of the individual living with dementia as a member of the care team to ensure his/her needs and wishes are represented as Alzheimer’s disease progresses. A cooperative care team may help to reduce stress for families affected by dementia and increase confidence that the needs and wishes of the person living with Alzheimer’s or other dementia are being met.

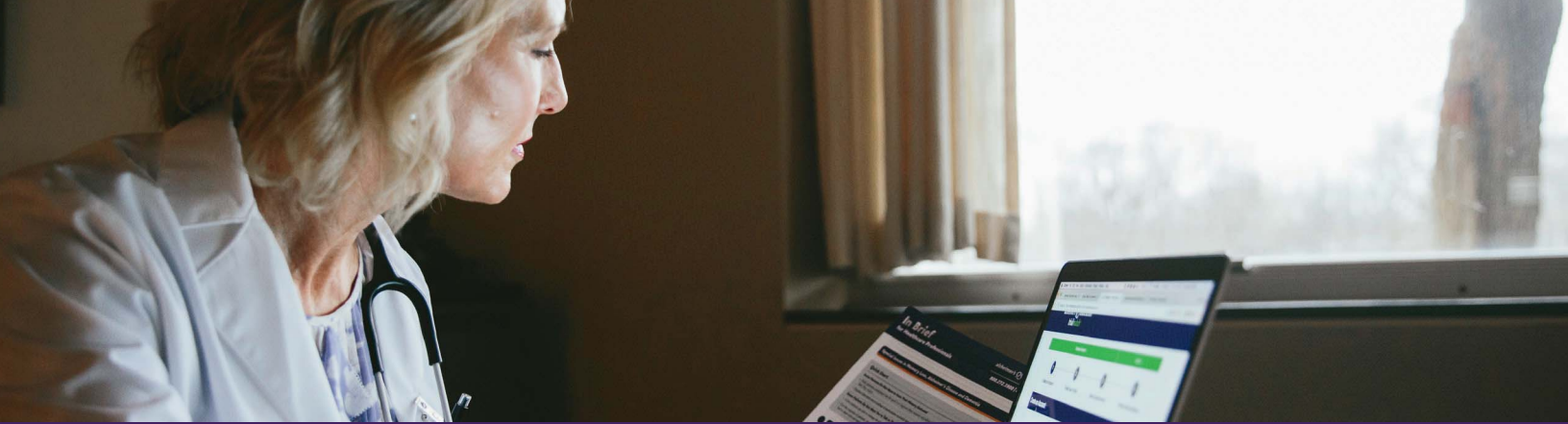
PERSPECTIVES OF PEOPLE LIVING WITH DEMENTIA

From the perspective of individuals living with dementia, person-centered care coordination includes attempts to obtain direct information from the diagnosed person and others who have direct knowledge of their diagnostic experience. People living in the early stage recommended direct care providers, including physicians or specialists, “spend time with me” to listen and evaluate current needs and consult with others who can provide insights. One person suggested, **“Ask questions, conduct surveys, review previous medical records, and talk with family and/or care partners or caregiver.”**

For individuals living with dementia, a strong working relationship with members of their care team requires collaboration and coordination among participants to not only gather information, but also to share necessary details with each other. People in the early stage expect that care providers will “Stay in touch with my current progress” and communicate effectively with others to share timely and accurate information. As one person suggested, “Coordinate with other care professionals; refrain from treatment teams giving mixed messages about our diagnosis.”

As Alzheimer’s progresses, individuals living in the early stage expect to rely on their care team to work collaboratively to address transitions in care. Family members are viewed as a critical component of their care team during a transition in care, and as one individual stated, **“Keep in close contact with my caretaker to ensure knowledgeable parties are included in discussion.”** According to another person, “I would want my doctor to listen to any concerns of the staff and my family and suggest therapies that might make me more comfortable.”

Individuals living with dementia also expressed that effective coordination among those delivering care provides reassurance that the individual’s needs will be met throughout the course of the disease. They recommended that care coordination include the individual perspective of the diagnosed person as well as ongoing communication with other care team members who provide support.



Train Staff on the Most Current Disease Information and Practice Strategies

Each person experiences the symptoms and progression of Alzheimer's or another dementia differently. For staff providing dementia care, current disease education and practice strategies are essential to understand how to apply personalized approaches to maintain quality of life for individuals living with dementia. **Appropriate training can also help build strong relationships and trust between care providers and individuals living with dementia.**

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Individuals living with dementia expect person-centered care to include recognition of the unique challenges and experiences that accompany Alzheimer's and dementia. **"We need to be treated as individuals,"** reported one respondent. Another person shared, "Staff need to understand that we're all different, just as patterns of Alzheimer's are."

Individuals living with dementia also responded that quality dementia care means understanding the basics of dementia, progression of Alzheimer's disease, behaviors and appropriate intervention techniques. They want staff to receive thorough training on a variety of topics including social engagement, pain management and therapeutic fibbing to be prepared to "tailor their approaches." They expect staff to engage fully in each encounter with the diagnosed person and "Always look beneath the surface."

People with dementia want to have confidence in the skills and resources of the staff providing care. They indicated that properly trained staff increased their confidence in the care provider's ability to deliver quality dementia care. According to one individual, **"Your skill is my only resource/recourse for peaceful self-acceptance and co-existence. You must help me preserve my self-dignity!"** They also stated that they depend on staff to receive the most up-to-date dementia education and training techniques. They expect training to include a person-centered care approach and investigation of the ways in which dementia impacts daily life.

“We need to be treated as individuals.”

“Your skill is my only resource/recourse for peaceful self-acceptance and co-existence. You must help me preserve my self-dignity!”



Inform and Include the Individual in New Interventions as Appropriate

Beginning in the early stage of Alzheimer's, diagnosed individuals and their care partners have a shared goal to help maintain the health of the individual living with dementia for as long as possible. In addition to ongoing regular assessment and evaluation, this includes receiving information on the most current and personalized intervention options, both pharmacological and non-pharmacological. This type of information can help individuals and families feel empowered to make the most well-informed choices around care and provides reassurance that their care team is providing the most current and available options.

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According to individuals living with dementia, quality care should include ongoing engagement with care professionals to identify the best intervention strategies to manage overall health and dementia diagnoses. Interventions should be reevaluated and modified as Alzheimer's disease progresses to meet the goals of the individual with dementia. For example, many people reported, "I want everything to be done to keep me as healthy as possible." However, as Alzheimer's disease progresses, care providers need to understand the individualized perceptions of benefits versus risks and tailor their approaches to match. As one person shared, **"My concern is that the doctor will prescribe therapies/medications that are not efficacious and have unpleasant side effects."** For example, "I know of many people who are taking Alzheimer's medications beyond the time in which they are helpful."

Those living in the early stage of Alzheimer's reported a high degree of confidence in their doctor's ability to manage their condition and medications, but in order to maximize their health they reported dependence on "the expertise of providers ... to suggest therapies that might help me." For some, this expertise came in the form of knowledge around clinical studies. Many individuals recognized the value that these studies provided through access to current treatments, medical monitoring and care coordination and expect their care providers to help identify appropriate studies. They also expect their care provider to not only have specialized knowledge of Alzheimer's and other dementias, but also to be "well-versed on ongoing studies."

People living with dementia want to be sure that care providers also consider intervention strategies that reflect the individual's preferences or personal beliefs. This may include non-pharmacological approaches that focus on behavioral interventions or holistic medicine. As one person summarized, "Since I've spent my adult life not a believer in drugs as a solution, I expect that holistic and alternative means of coping with medical conditions will be given top and first considerations."

At present, there is no way to prevent, cure or even slow Alzheimer's disease. However, for those living with dementia, the desire to identify and connect with personalized, appropriate and innovative interventions provided a sense of empowerment and hope for the future. Taking steps to engage with appropriate interventions helps to establish a sense of control over the experience of living with dementia.



Create a Safe and Supportive Environment That Reflects the Person's Characteristics, Personality and Preferences

The experience of living with Alzheimer's or another dementia includes increased sensitivity to sensory experiences that are unfamiliar or overwhelming. Environmental factors like crowds and excessive stimulation can trigger behavioral and psychological symptoms of dementia (BPSD) such as anxiety or increased confusion. These symptoms can be uncomfortable for the individual living with Alzheimer's, or dementia may lead to unsafe reactions like wandering or agitation. A person-centered care approach for a home or residential environment involves minimizing or reducing environmental factors that may lead to BPSD and including individual preferences for a "home-like" atmosphere. Support for individual preferences may reduce BPSD and provide reassurance of safety and comfort as Alzheimer's disease progresses.

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Current lifestyle preferences and the challenges of living with dementia are factors that shaped individuals' expectations for future care environments. A quiet and calm environment — whether in a home or a residential facility — is important to individuals as they consider qualities of a safe and supportive living space. People who are living in the early stage of Alzheimer's or with another dementia perceive BPSD as an expected consequence triggered by excessive or unfamiliar stimulation such as noise, light or congested environments. As one person described, "Noise, commotion, etc. all add to the effects of the disease." Many individuals reported that they have found ways to minimize these triggers in their daily lives by avoiding crowds, sticking to a routine and not overcommitting to activities. As one individual described, "I cannot stand being in a chaotic, noisy environment. I have earplugs that provide some relief, but it's hard. I prefer to shop in the same store where I know the layout and can find what I need and get out ASAP."

As Alzheimer's disease progresses, individuals living in the early stage stated a desire to limit or reduce the anxiety and frustration caused by environmental factors to ensure a good quality of life in the later stages. An environment that provides a quiet and even private space for the individual was described as a way to reinforce feelings of safety and support. According to another respondent, **"I think that a calm environment and a space to call my own will help me to cope."**

In order to make an environment feel like home, individuals living with dementia expect to be able to personalize their space to reflect individual tastes and preferences. Personal items such as music, books, furniture and pets or family members are components of an environment that were reported as providing comfort. As one person described, "One way I can think of to support me is to make sure that I have personal treasures that move with me — photos, bedding, a chair — things that will ground me in my past and make me feel safe and secure." Personal possessions including family photos and other items were described as providing a sense of familiarity and comfort. Meaningful relationships and activities also were said to provide feelings of security in a home-like environment. Lastly, varied and available activities, as well as access to outdoor space, were viewed as opportunities for meaningful engagement. According to one individual in the early stage, **"Living long is meaningless to me unless it also means living comfortably."**



Conclusion

Care providers have a unique opportunity to change the way individuals and families experience living with Alzheimer's or other dementias by incorporating person-centered care into their normal practice. Person-centered care is achieved when the preferences of the individual living with dementia remain at the core of caregiving. It also requires that the focus of care is flexible and can be adjusted based on the needs of the individual living with dementia rather than the needs of the care provider.

For individuals living with dementia, person-centered care involves maintaining a sense of autonomy and control over one's life and is essential to living a quality life throughout the course of the disease. In the early stage, the person living with Alzheimer's is able to participate in decisions that can help care providers understand their needs and preferences and how they want to receive support. As Alzheimer's disease progresses, care providers will need to involve family members and other members of the care team to act as informants to ensure the needs and preferences of the individual remain at the core of person-centered care. In the late stage of Alzheimer's disease, even as communication becomes significantly impaired, the individual living with dementia may rely on nonverbal communication such as facial expression or vocal sounds to communicate their needs and preferences.

For people living with dementia, person-centered care practices need to begin at detection and diagnosis and continue through to end-of-life care. Practicing person-centered care can help care providers better support individuals with dementia and their families and enhance their overall quality life throughout the course of the disease.

For more information about person-centered care and other best practices for dementia caregiving, please visit [alz.org/qualitycare](https://www.alz.org/qualitycare).

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