

A Practical Guide to Person-Centered Dementia Care for Care Professionals

What is person-centered care and why is it important?

Person-centered care is a philosophy of care that recognizes each person living with dementia as an individual. It challenges the traditional medical or staff-directed model of care that tends to focus on processes, schedules, staff and organizational needs. Person-centered dementia care *tailors support to the unique needs, preferences and abilities* of individuals living with dementia, while also addressing the specific needs of their caregivers through an individualized, family-centric approach.

This personalized approach includes understanding the preferences of the individual with the diagnosis and how they'd like to be referred to in terms of their diagnosis. Some individuals prefer to be referenced as living with or diagnosed with a cognitive impairment, while others prefer using the specific medical terms such as dementia, Alzheimer's disease or other specific diagnoses. This is important to mention as we look at preferences of the individual and how they perceive the use of the different diagnoses. For this document, we will use the term "living with dementia" as a general term to indicate someone living with a cognitive diagnosis, such as Alzheimer's disease or another dementia, and again, encourage others to learn how an individual wishes to be referenced.

Whether referred to as "person-directed," "resident-focused" or something similar, the core principles are essentially the same.

Simply stated, person-centered care is about treating people the way that *they* want to be treated and the concepts cross over to working with individuals living with dementia in day-to-day engagement.

What is the history of person-centered care?

Person-centered care is not a new concept.

Some highlights include:

- **1940**
The idea originated with the work of psychologist **Carl Rogers**.
- **1988**
Thomas Kitwood introduced a care approach different from medical and behavioral approaches to dementia.
- **Early 2000s**
Dawn Brooker outlined four key components that are integral to a person-centered care approach for people living with dementia that can result in a shift in practice and culture.

Valuing and respecting persons living with dementia and those who care for them.

Seeing the world from the perspective of the person living with dementia, so as to understand the person's behavior and what is being communicated, and validating the subjective experience that is being perceived as the reality of the individual.

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Treating people living with dementia as individuals with unique needs.



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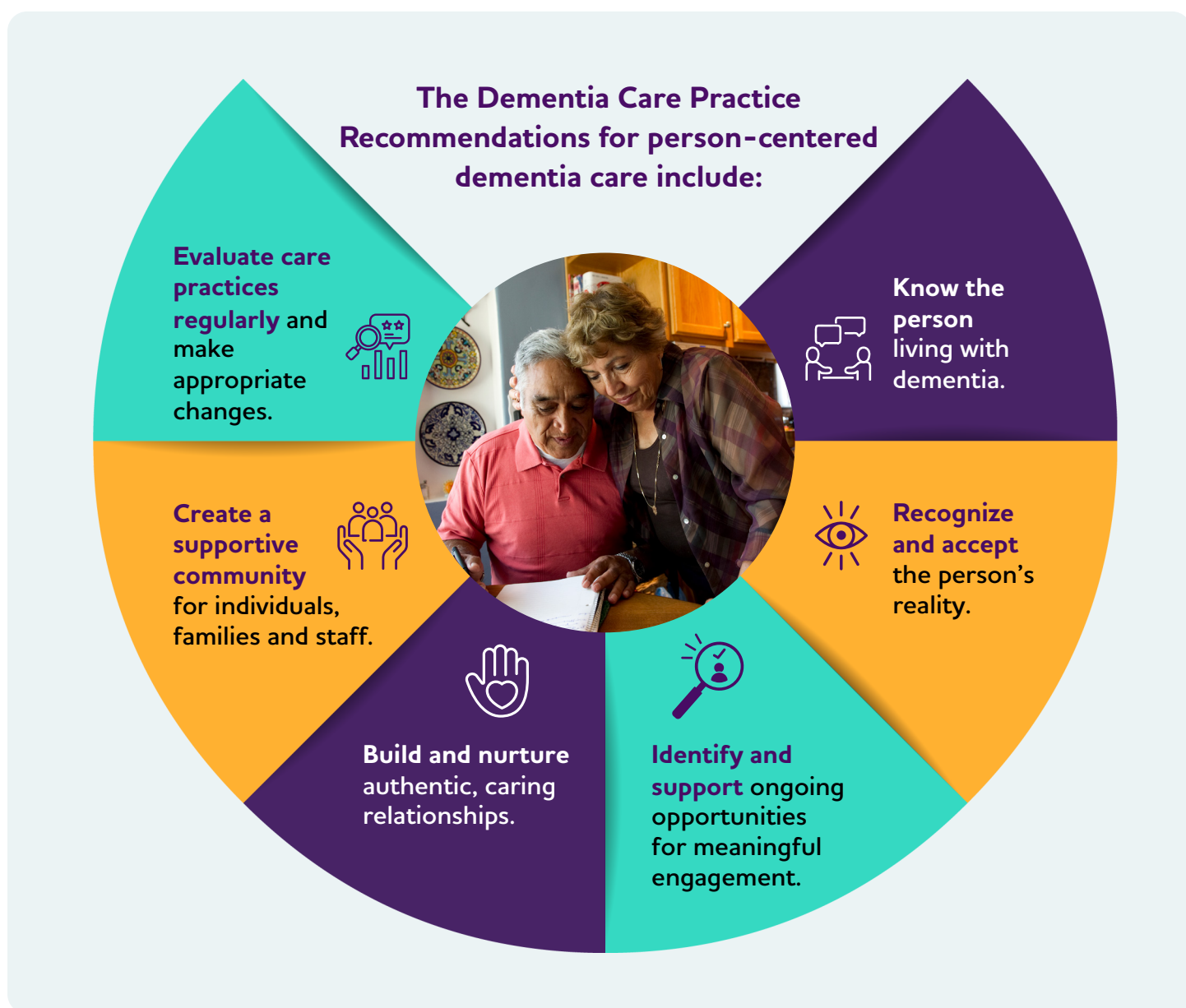
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Creating a positive social environment in which the person living with dementia can experience relative well-being through care that promotes the building of relationships.

How is the Alzheimer's Association® influencing person-centered dementia care?

Since its inception, the Alzheimer's Association has been a leader in outlining principles and practices of quality care for individuals living with dementia. Early on, the Alzheimer's Association Guidelines for Dignity described goals for quality care, followed by Key Elements of Dementia Care: Residential Living, End-of-Life Care and Professionals Working in a Home Setting. Then most recently, the Association launched the [Dementia Care Practice Recommendations](#) as more evidence became available. In this newest iteration, the Alzheimer's Association Dementia Care Practice Recommendations outline recommendations for quality care practices based on a comprehensive review of current evidence, best practice and expert opinion. These recommendations are the foundation of our products and services related to care professionals in a variety of settings.

The Dementia Care Practice Recommendations were developed to better define quality care across all care settings and throughout the disease course. They are intended for professional care providers who work with individuals living with dementia and their families in long-term and community-based care settings. The Alzheimer's Association Dementia Care Practice Recommendations were published as a supplement to *The Gerontologist*, a journal of the Gerontological Society of America that publishes applied, multidisciplinary research and analysis on social issues related to human aging. The Dementia Care Practice Recommendations are the foundation for the Alzheimer's Association products, such as [essentiALZ® - Alzheimer's Association training and certification](#), [curriculum review](#) and [Project ECHO® for Professional Care Providers](#).





A Guide to Quality Care from the Perspectives of People Living with Dementia

is an important publication from the Alzheimer's Association® that supports the importance of caring for an individual as they want to be cared for.

This guide was created with input from the National Early-Stage Advisory Group, a community of people living with early-stage Alzheimer's or related dementias, in an effort to better meet individuals' needs throughout the disease course as told from the perspective of individuals living with dementia.

Visit the [CMS page](#) to access other publications that support care professional work.



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What is person-centered language?



Person-centered language is a critical component of person-centered dementia care and helps create a culture change within a care community.

The following best practices should be considered:

- ✓ **Use “person-first” language:**
Focus on the individual, not only their disease or diagnosis. For example, use “person living with dementia.”
- ✓ **Focus on the individual experience:**
Consider the likes, dislikes and preferences of the individual and how that might be influencing their experience living with the disease.
- ✓ **Focus on abilities, not deficits:**
Rather than highlighting what the person can no longer do, consider what they can do, or their current strengths.
- ✓ **Refrain from using labels or generalizing terms:**
Labeling or generalizing an individual can lead to depersonalization or oversimplification of the experience or need.
- ✓ **Speak directly to the person:**
Especially in the early stages of dementia, it is important to include the person in the conversation rather than speaking about them to their care partner or other individuals who offer support.



Communication/language tips for care professionals:



Person-centered care language can help care professionals:



Why does the language I use matter?

The language we use to describe individuals living with Alzheimer's and dementia affects our thoughts which then impacts our actions. Language that generalizes, blames or demeans people living with dementia not only oversimplifies the disease experience, but further stigmatizes individuals. **Focus on the person as a whole, not just the disease.**

Below are a few examples of inappropriate and appropriate language to describe individuals living with dementia*.

Inappropriate

Terms or descriptions which are overtly medical in nature or dehumanize the person living with dementia. Examples could include:

- Patient
- Admit/admission
- Demented person
- Referring to them by their room number

Terms or descriptions which infantilize or label the person living with dementia. Examples could include:

- Honey/sweetie/cutie
- Childlike
- Hoarder
- Wanderer
- Feeder

Terms or descriptions that evoke a sense of diminished value, worth or contribution. Examples could include:

- Loss/losses
- Broken/failed brain
- Weaknesses
- Inabilities
- Impairments
- Problem

Descriptions that imply behaviors are intentional and burdensome for staff. Examples could include:

- Problem behavior
- Stubborn
- Catastrophic reactions
- Manage behavior
- Obstinate/noncompliant

Actions taken by direct care staff to engage with individuals living with dementia. Examples could include:

- Doing for
- Distract
- Therapeutic fib

Appropriate

Terms or descriptions that identify the person rather than the disease. Examples could include:

- Person living with dementia
- Individual living with dementia

Terms or descriptions that promote dignity, respect and autonomy. Examples could include:

- Individual who collects items
- Individual experiencing wandering
- Individual who needs assistance with eating

Terms or descriptions that promote dignity, respect and autonomy. Examples could include:

- Current strengths and abilities
- Progression of the disease

Terms or descriptions that recognize behavior as a form of communication. Examples could include:

- Behavioral expressions
- Dementia-related behaviors
- Addressing or supporting a behavior

Terms or descriptions that support person-centered engagement. Examples could include:

- Doing with
- Redirect
- Join the person in their reality

*Adapted in part from the University of Minnesota, Center for Practice Transformation <https://practicetransformation.umn.edu/practice-tools/person-centered-language/>



What can I do to influence person-centered care and create change in my community?

- ✓ **Share this information** with co-workers and leadership to see how you might integrate these learnings into your day-to-day interactions, collateral and communications.
- ✓ **Review other resources**, such as the [Pioneer Network](#), and learn appropriate ways to use language related to aging and dementia.
- ✓ **Take the person-centered self-assessment** as an individual or organization to see where opportunities to engage in additional person-centered practices may exist.
- ✓ Visit alz.org/qualitycare to learn more about the Alzheimer's Association resources that support person-centered culture change, including [essentiALZ®](#): person-centered dementia training and certification, [Project ECHO](#): peer-to-peer learning cohorts and other tools based on the Dementia Care Practice Recommendations.



For additional information and professional resources, visit alz.org/ALZPro.