

# Equity and Inclusion Considerations for Dementia Care Planning

Equitable and inclusive dementia care planning involves a comprehensive approach that considers the unique needs, living situations, social factors, circumstances, and culture of individuals living with dementia, their care partners, and families. In this document, "culture" is understood from a multifaceted perspective encompassing various dimensions beyond race and ethnicity. It includes historical narratives shaped by institutionalization, marginalization, bias, and discrimination, which profoundly influence individuals and communities. Moreover, culture extends to encompass gender identities, differing abilities, disabilities, religious beliefs, socioeconomic backgrounds, sexual orientations, and other facets that shape an individual's worldview and lived experiences. Recognizing this expansive understanding of culture is imperative for health care providers in developing inclusive and effective care plans that honor the diversity of each person's identities and experiences.

Below is a list of equity and inclusion considerations for dementia care planning. The list is not intended to be exhaustive; and the considerations do not appear in any particular order.

## **Stigma and Cultural Sensitivity**

- Conduct open and non-judgmental discussions about the patient's cultural perceptions about dementia; and address concerns about stigma that stem from the patient's cultural beliefs.
- Use culturally appropriate language and examples that resonate with the patient's culture; create opportunities for the person to tell their story in their own way.

- Empower the patient and care partners to feel comfortable sharing their experiences and insights about dementia within their own cultural context.
- While considering cultural beliefs around dementia, keep in mind that individuals may interpret and express beliefs in a unique way based on their own personal experiences and perspectives.

### **Cultural Humility**

- Avoid imposing your own beliefs on the planning process and care plan. Be cognizant of your power and privilege, cultural assumptions, and prejudices while identifying care and service options. Recognize and respect that the patient's values and culture may not align with the values and cultural biases of the health care system.

### **Communication and Language**

- Foster communication that ensures patients feel seen, heard, understood, and valued.
- For patients who are not confident conversing and/or reading English, use medical interpreters when possible during care planning discussions and provide written documentation about the care plan in the patient's language.
- Create visual materials such as infographics, videos, and pamphlets to supplement written information. Ensure visuals are inclusive and represent diverse ethnicities, ages, and genders.
- Consider various formats for information dissemination, including large print, audio recordings, and accessible digital formats for those with low vision or hearing loss.
- Allow extra time to enable communication with patients living with dementia, and with patients or care partners where there may be a language barrier.

## Health Literacy

- Assess the health literacy level of the patient, family, and care partners; and adjust the complexity of language used; and include a care partner and a medical interpreter when possible.
- Use plain language and clear, concise, and specific examples whenever possible, avoiding jargon and complex medical terminology to enhance understanding.
- During discussions with the patient, include care partners and include a medical interpreter when possible. Solicit feedback from the patient and care partners to understand how well the care planning information is understood.
- Consider that the patient may have rarely or never met with health care providers in their lifetime.

## Beliefs about Medication

- Identify and address any specific cultural beliefs that the patient may have about medication use. For example, traditional or alternative medicine may be preferred over pharmaceuticals in certain cultural communities.
- Become aware of the patient's cultural beliefs that may impact willingness to take prescribed medications; and tailor the patient's dementia care plan to align with their preferences.

## Family Involvement

- Understand and respect the family's decision-making dynamic. In some cultures, family plays a significant role, and their involvement can enhance adherence to the patient's care plan. Respect the patient's and family's cultural beliefs around the role of family members in caregiving.
- Recognize potential generational variations in cultural beliefs within a family regarding preferences and attitudes about dementia, care planning, and health care in general. Some family members do not use the term "caregiver" because caring for a relative is considered a natural obligation and not a specific role.
- Recognize and respect that in some cultures, the well-being of the family is prioritized over individual desires.
- Understand and respect the patient's definition of family as the definition differs across cultures.

**Traditional Healers and Religious, Spiritual, and Cultural Practices**

- Some individuals may consult traditional healers alongside conventional medicine. The care plan should include any concurrent non-conventional treatments and ensure they do not interfere with prescribed medications.
- Understand the patient's religious or spiritual practices; incorporate them into the care plan to foster trust and cooperation.

**Referrals to Community Services and Supports**

- Include culturally appropriate services, supports, and meaningful activities in the care plan that foster a sense of belonging and comfort by respecting and incorporating preferences around language and cultural traditions.
- Prioritize referrals to community resources that are culturally competent and inclusive.
- Identify social risk factors that may impair the dementia patient's cognitive functioning or general health and wellbeing; and refer dementia patients and caregivers to culturally appropriate community services and supports that can address unmet social needs.

**Assessing Cognitive Function**

- In conducting assessments of cognitive function, consider linguistic and cultural nuances that may impede an accurate assessment.
- Employ culturally appropriate communication approaches such as interpreters to ensure clarity during cognitive assessments. Use culturally sensitive questioning techniques, such as incorporating familiar cultural references.

**Dietary Considerations**

- Account for cultural dietary preferences and restrictions in nutrition plans.
- Understand that some cultures have dietary restrictions that may affect food or medication preferences. Ensure that the care plan respects a patient's culturally appropriate dietary preferences and restrictions.

### **Assessing Behavioral Health**

- Address cultural stigmas surrounding mental health by fostering an environment where individuals and families feel comfortable discussing behavioral health concerns.

### **Cultural Competence in Advanced Care Planning and Palliative Care**

- Ensure that dementia care planning aligns with the patient's cultural beliefs around advanced care planning and palliative care. Respect diverse cultural perspectives on end-of-life decisions.

### **Community Engagement**

- Engage with local communities to understand cultural needs and preferences around dementia care and care planning; and host discussions in culturally relevant community spaces.
- Leverage trusted figures within cultural communities to enhance the credibility and acceptance of dementia care and care planning.