

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

INFORMED CONSENT TO DEMENTIA CARE & SERVICES

FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Personal autonomy – the ability to make choices about one’s own life – is important to everyone. A diagnosis of dementia does not diminish a person’s desire to have control over their decisions, especially those related to health care and daily life. In fact, as cognitive abilities change, maintaining a sense of autonomy can become even more essential to a person’s dignity and well-being.

Cognitive impairment can make it more difficult for individuals to fully understand options, express preferences, or make complex decisions. This may lead family members or professionals to step in and make choices on their behalf. While often well-intentioned, this can unintentionally undermine the individual’s rights and preferences.

This fact sheet offers practical guidance on understanding and applying the principles of informed consent in dementia care. For additional tools and resources, visit nursinghome411.org/dementia-care-in-the-community.

What is Informed Consent?

Informed consent is a foundational principle in care. It ensures that individuals understand and agree to the care and services they receive. For people with dementia, this means actively involving them—alongside their families—in conversations about their care. It's not only respectful but also essential for person-centered, values-based care.

- **Informed** = Providing the information on a plan of care or proposed treatment in a way that the recipient can understand. Information includes the risks and benefits of the proposed treatment as well as the risks and benefits of alternative treatments.
- **Consent** = The individual or their designated surrogate makes the final decision, regardless of whether those decisions align with the care provider's recommendations.

WHAT IS INFORMED CONSENT?

“Informed consent is an ethical concept—that all patients should understand and agree to the potential consequences of their care—that has become codified in the law and in daily practice at every medical institution.”

- [A Practical Guide to Informed Consent](#)

How Does This Align with Professional Standards of Care?

Professional care standards emphasize the importance of informed consent to ensure that individuals' right to make decisions over what care they will or will not receive is honored. This approach involves actively partnering with people living with dementia and their families to help them make well-informed decisions based on the individual's preferences, values, and health goals, promoting autonomy and tailored care outcomes.

Best Practices for Supporting Autonomy

- **Start with Respect:** Assume capacity. Always begin by involving the individual in decisions to the greatest extent possible.

- **Simplify Communication:** Use clear, simple language, visuals, or other tools to help explain choices.
- **Offer Support, Not Substitution:** Instead of making decisions *for* someone, make decisions *with* them whenever possible.
- **Know Their Values:** Understanding what matters most to the individual can guide care that aligns with their goals.
- **Involve Trusted Others:** Family members, friends, and advocates can help bridge communication and support informed choices.
- **Document Preferences:** Advance care planning and documented preferences help ensure care reflects the person's wishes, even if decision-making becomes more difficult.

Legal Documents

Legal documents can play a crucial role in ensuring that the wishes and values of a person with dementia are honored as the disease progresses. They also empower trusted individuals to make decisions on their behalf when the person is no longer able to do so. For a helpful overview of key documents—such as powers of attorney, living wills, and other tools that support future planning—visit the Alzheimer's Association's Legal Documents page at <https://www.alz.org/help-support/caregiving/financial-legal-planning/legal-documents#power>.

Tips for Putting Informed Consent into Practice

- **Include the Individual.** Support the person with dementia in participating in care planning. Ask providers to explain options in clear, simple terms.
- **Respect Preferences.** Advocate for care that honors the individual's values, goals, and dignity. Make sure their voice and priorities are central in all decisions.
- **Be Informed.** Learn about the person's health conditions, treatments, and care options so you can support informed, values-based choices.
- **Ask Questions.** Speak up! Ask about risks, side effects, alternatives, and long-term outcomes. The more you know, the better you can support informed decisions.
- **Work as a Team.** Promote collaboration among the individual, family members, and care providers. A shared approach leads to more personalized and respectful care.
- **Honor the Right to Choose.** The individual (or their representative if they have designated one) has the final say. **Any decision that directly affects the patient's physical or mental functioning or has more than minimal risk is subject to informed consent.** Even if a provider disregards informed consent protocols, the individual should always feel empowered to reject a proposed treatment or advocate for one not offered.