

A photograph of an elderly man with white hair and a beard, wearing a white hospital gown, sitting up in a hospital bed. He is looking towards a young woman with blonde hair tied back, who is wearing a white sweater and looking at him. The background is a bright, out-of-focus room with a window and some flowers.

End-of-Life Decision Making Using Five Wishes To Guide Advance Care Planning

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Participants will:

- Understand the challenges associated with end-of-life conversations as they relate to guardianship.
- Recognize the importance of using an advance directive tool early in the relationship to know the end-of-life wishes of the person under guardianship.
- Learn how Five Wishes works with NGA's Ethical Principles and Standards of Practice.

End-of-life can present challenging ethical dilemmas for the dying individual as well as the guardian. Among decisions that guardians are tasked with end-of-life are ranked among the most challenging.

Why?

- Uncertainty of the person's wishes
- Isolation
- Inadequacy
- Pressure
- Frustration
- Possible language or cultural barrier
- With no knowledge of a person's wishes, preferences or goals decisions are made using the traditional best interest standard which is not always the person's wishes, expressed or not expressed.

Jack

- 66 y/o white male
- Estranged from family
- Minimal social and family hx
- Hx of living in homeless shelters
- Currently resides in a nursing home
- Under guardianship 3 years



Jack

- Liver Cirrhosis
- Seizure Disorder
- Atrial Fibrillation
- High Cholesterol
- High Blood Pressure
- Coronary Artery Disease
- Kidney Failure – Hemodialysis
- Memory Loss due to hx of excessive alcohol abuse



Challenges associated with end-of-life conversations as they relate to guardianship.

- Little to no prior knowledge of the person under guardianship
- Isn't the right time
- No knowledge of end-of-life wishes
- No understanding of the course of an illness, is it terminal, is death immanent
- Uncomfortable having a conversation about death
- Stigma surrounding end-of-life, often influenced by cultural identity
- General misunderstanding of end-of-life terms and what they entail

The importance of using an advance directive tool early in the relationship to know end-of-life wishes

Primary end-of-life medical questions and issues a guardian may encounter:

- Code status
- Withdrawing and withholding of life-sustaining interventions
 - Resuscitation by chest compressions, mechanical ventilation, artificial nutrition artificial hydration, dialysis
- Medical futility



The importance of using an advance directive tool early in the relationship to know end-of-life wishes

➤ ***Enables the guardian to***

- Be prepared ahead of time, before the crisis
- Have an understanding of the persons hopes and fears around illness and dying
- Use specific beliefs to guide the decision-making process
- Prevent multiple unwanted hospitalizations
- Prevent futile or unnecessary procedures
- If someone has been previously diagnosed with an illness, it's important to assess their understanding of the illness
- Provide decisions that are consistent with what the person would have wanted
- Give vital information to medical providers
- Implement Palliative and Hospice Care early in the disease
- Improve QOL
- Allow the person to die with dignity

How does Five Wishes work with NGA's Ethical Principles and Standards of Practice?



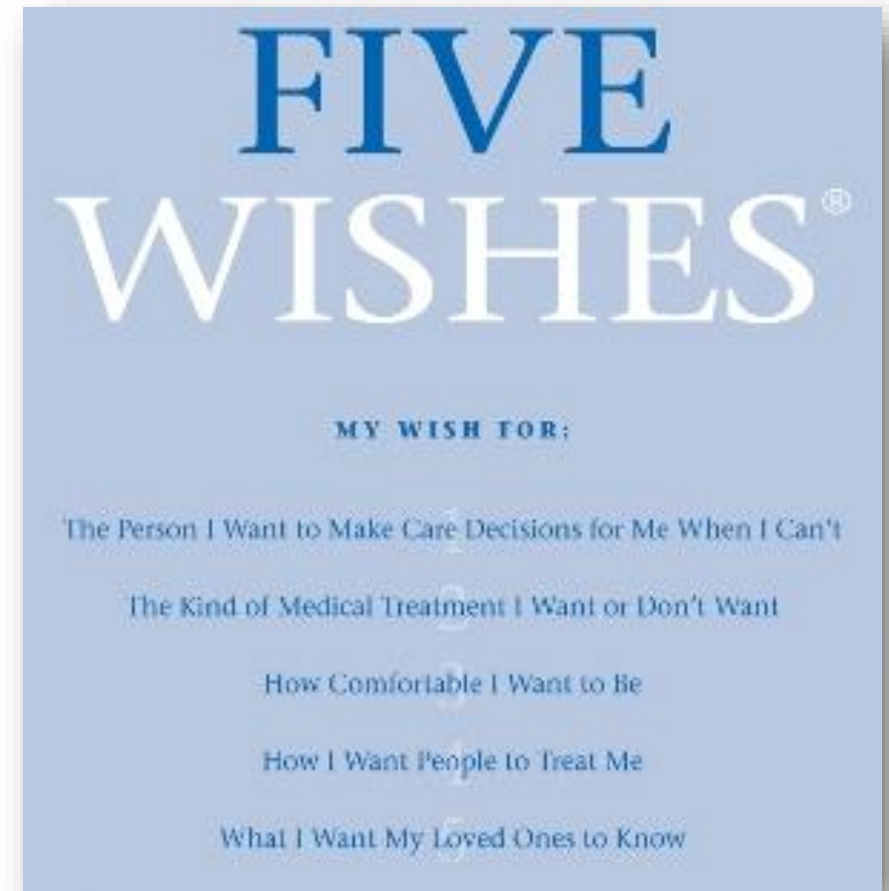
FIVE WISHES®

a program of



Ensuring human dignity through conversations that matter

- Aging with Dignity was founded in 1996 with a mission to:
 - *Safeguard and affirm the human dignity of every person who faces the challenges and opportunities of aging or serious illness.*
- It's more than just a document. Five Wishes is a complete approach to discussing and documenting your care and comfort choices. It's about connecting families, communicating with healthcare providers, and showing your community what it means to care for one another.



Ethical principles

A guardian identifies and advocates for the person's goals, needs, and preferences.

NGA Standard 7

Standards for Decision-Making

- The guardian shall ask the person what he or she wants.
- If the person has difficulty expressing what they want, the guardian shall do everything possible to help the person express their goals, needs, and preferences.

Five Wishes

- It's written in everyday language, making it easy to understand and complete.
- It covers personal, spiritual, medical, and legal wishes all in one document.
- Culturally aware and available in 29 different languages, as well as Large Print and Braille.
- Specifically designed to facilitate difficult conversations, and backed by the support of the nation's leading experts on advance care planning.
- It allows an individual's family, caregiver, or guardian to know exactly what they want, relieving them from the difficult position of guessing what the person's wishes might be.

Ethical principle

A guardian involves the person to the greatest extent possible in all decision-making.

NGA Standard 9 **Self-Determination of the Person**

- The guardian shall encourage the person to participate, to the maximum of their abilities, in all decisions that affect him or her, to act on their behalf in all matters in which the person is able to do so.
- The guardian shall wherever possible, seek to ensure that the person leads the planning process; and at a minimum to ensure that the person participates in the process.

Five Wishes

- The mission of Aging with Dignity is to preserve the **dignity** of **all** people.
- Advance care planning increases the amount of control an individual retains over their own care.
- Using *Five Wishes* ensures that a person's choices and preferences surrounding medical care, treatment, comfort, and legacy are preserved.



Guardians & *Five Wishes*



- Protect the voices of those they care for.
- Demonstrate that they are actively encouraging the individual's participation in the planning process.
- Provide a holistic look at what matters most to the person they care for.

Ethical principle

A guardian identifies and advocates for the person's goals, needs, and preferences.

NGA Standard 14

Decision-Making About Medical Treatment

- To the extent the person cannot currently direct the decision, the guardian shall act in accordance with the person's prior general statements, actions, values, and preferences to the extent actually known or ascertainable by the guardian.

Five Wishes

- Promotes **person-centered** health care decision-making.
- Provides a roadmap of care that reflects the wants and needs of the person who's care is in question.
- Ensures that a conversation has been had regarding health care decisions.



Guardians & *Five Wishes*



- Able to have a guided, less intimidating conversation with the individual about their values and preferences.
- Relieve themselves from the difficult position of guessing the individual's wishes.
- Maximizes & records the participation of the person in guiding their own care.

Five Wishes Resources:

- [Five Wishes](#)
- [Conversation Guide for Individuals & Families](#)
- [Conversation Guide for Clinicians](#)
- [Sharing the Gift: Presenter's Guide](#)
- [Five Wishes DVD](#)

Five Wishes is Available in: Albanian, Arabic, Armenian, Bengali, Chinese – Simplified, Chinese – Traditional, Croatian, English, Farsi, French, German, Gujarati, Haitian Creole, Hebrew, Hindi, Hmong, Ilocano, Italian, Japanese, Khmer, Korean, Polish, Portuguese, Russian, Somali, Spanish, Tagalog, Urdu, & Vietnamese



Additional Resources:

- **Aging With Dignity:** www.agingwithdignity.org
- **Five Wishes:** www.fivewishes.org
- **The American Bar Association:** *Myths and Facts About Health Care Advance Directives*
https://www.americanbar.org/groups/law_aging/publications/bifocal/vol_37/issue_1_october2015/myths_and_facts_advance_directives/
- **National Institutes of Health:** <https://www.nih.gov/>
- **MyDirectives:** MyDirectives helps consumers record their medical treatment wishes, preferences regarding palliative and hospice care, organ donation, and autopsy, and other critical personal information both on the device, and in the format, that is most convenient and comfortable for them.
 - Hard copy *Five Wishes* documents can be scanned and uploaded to MyDirectives here:
https://mydirectives.com/fivewishesNHDD?utm_source=FiveWishes&utm_medium=Banner