

# Making Difficult Decisions about the End of Life: Continuing and Emerging Challenges in Technological Societies

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# What does it mean to *do* ethics?

We are doing ethics when we:

- undertake critical reasoning about morality (right and wrong) in human conduct, including professional conduct;
- with reference to standards (such as principles); and
- apply our reasoning to a practical problem or the development of larger-scale guidance and policy.

“Medical ethics,” “biomedical ethics,” or “health care ethics” are ways to refer to ethics in the practice of health care professionals. “Bioethics” includes the health care context and other contexts, such as scientific research.

# Why the end of life is (or should be) central to ethics education in medicine

1. The end of life is a human experience that raises the deepest questions about human conduct and its consequences for other people:
  - How should we care for one another?
  - How should we use technology in the face of our mortality?
  - What do societies owe their ageing members?

# Why the end of life is (or should be) central to ethics education in medicine

2. The end of life is a complex personal and family experience. Health care professionals will *frequently* encounter patients and families grappling with practical decisions that challenge their ideas about right and wrong.

- The family of a now-incapacitated patient may be unsure or in conflict about how to translate devotion and familial duty into the medical context: Is more, better? Is it right to say “enough” to suffering?
- Dying people and their families may experience grief in anticipation of death, adding stress to decision-making.

# Why the end of life is (or should be) central to ethics education in medicine

3. The end of life is a formative professional experience for young doctors and nurses.

- Hospitalised patients tend to be very sick, often due to progressive diseases of ageing.
- Professionals routinely face ethical uncertainty about what they should do for patients nearing the end of life, how they should respond to families' needs and requests/demands, and how they should think about the care problems they observe, including structural problems they cannot fix.

# How different is Asia? How similar is Asia?

“Research has revealed that although the concept of dying well varies among some individuals and cultures, there are some common factors.” Prof. Diana Lee, Nethersole School of Nursing, CUHK, *South China Morning Post*, 7 June 2014

Pain relief, having one’s treatment/care preferences respected, and receiving care that promotes dignity and supports well-being and family relationships are valued by people across Asian and Western societies.

How different is Asia?

How similar is Asia?

“As our population is ageing rapidly, there is an escalation of chronic diseases. Chronic illness care and management are becoming an increasingly important part of the health care agenda with regard to patients living and dying well.” Prof. Diana Lee, *South China Morning Post*, 7 June 2014

The ethical and social challenges resulting from population ageing are similar across Asian and Western societies.

How different is Asia?

How similar is Asia?

Across technological societies, a common constellation of ethical challenges includes:

- age-associated, chronic/progressive conditions;
- ready access to potentially life-sustaining interventions;
- uncertainty about how best to use these interventions as people age, become ill, and approach the end of life, and
- inadequate systems for the long-term realities of different chronic/progressive illness trajectories and their consequences for patients and families.

*The Hastings Center Guidelines for Decisions on  
Life-Sustaining Treatment and Care  
Near the End of Life*

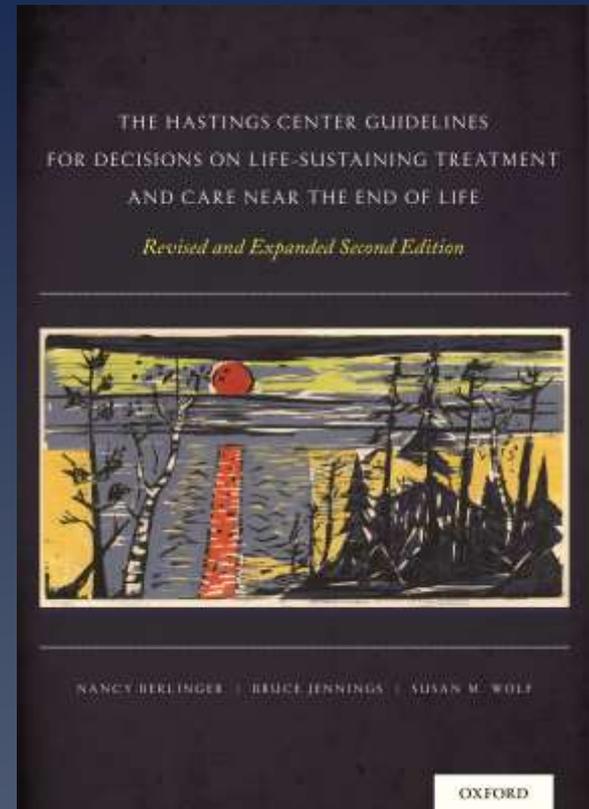
Revised and Expanded Second Edition  
Nancy Berlinger, Bruce Jennings, and Susan M. Wolf  
Oxford University Press, 2013

Available in English in Kindle and print editions  
from Amazon.

Korean (2015) and Japanese (2016) editions forthcoming.

Companion website:

[www.HastingsCenterGuidelines.org](http://www.HastingsCenterGuidelines.org)



# *The Hastings Center Guidelines:* Two Consensus Reports

## **First edition: 1987**

- First set of ethics guidelines on EOL care.
- Formulated pre-*Cruzan*.
- Helped consolidate decision-making rights of patients and authority of surrogates.
- From theory to practical decision-making pathway.
- Focus on “termination” of life-sustaining treatment.

## **Revised and expanded second edition: 2013**

- From pathway to complex practice realities.
- Reflects 25 years of learning.
- Formulated post-*Schiavo*.
- Focus on “decisions” about treatment, including chronic conditions.
- Adds perspectives on disability, pediatrics, systemic reform.

## Scope of the 2013 *Guidelines*

“These *Guidelines* concern **two groups** of adult and pediatric patients: **those who face decisions** about the use of life-sustaining treatment and care following such decisions, **and those who are near the end of life**, whether or not a decision about life-sustaining treatment is being considered. These two groups overlap, but are not the same.”

**All professionals who care for patients facing decisions about life-sustaining treatment are also part of end-of-life care systems.**

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- Legal & ethical consensus

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## Part Two: Guidelines on Care Planning & Decision-making

Section 1: Advance care planning & advance directives

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Companion website:

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# Summary of Ethics Goals

Goal 1: “Relieve suffering.”

Goal 2: “Respect the experience of living while supporting the process of dying.”

Goal 3: “Promote well-being.”

Goal 4: “Respect persons.”

Goal 5: “Respect dignity.”

Goal 6: “Respect relationships.”

Goal 7: “Respect difference.”

Goal 8: “Promote equity.”

Goal 9: “Preserve professional ethical integrity.”

Goal 10: “Use organizational systems to support good care and ethical practice.”

# Legal and Ethical Consensus (US)

**“Patients with decision-making capacity have a common law and constitutional right to refuse life-sustaining treatment.”**

(Established in *Quinlan*, 1976 and *Cruzan*, 1990; reflected in statutory law)

**“Patients who lack decision-making capacity have the same rights to refuse life-sustaining treatment as patients with decision-making capacity. The manner in which these rights are exercised is different, as a surrogate decision-maker must usually speak for them.”**

(Established in *Quinlan*, 1976, *Cruzan*, 1990; reflected in statutory law)

**“The right to refuse life-sustaining medical treatment does not depend on projected life expectancy, whether long or short. Patients have a basic right to be free of unwanted treatments.”**

# Legal and Ethical Consensus (US)

**“There is no ethical difference between withholding and withdrawing life-sustaining medical treatment.”** (The right to refuse includes the right not to start and the right to stop; both are ways to “forgo” treatment.)

**“No treatment or form of care is intrinsically ‘ordinary’ or ‘extraordinary.’”** (Presenting treatment and care decisions in term of “benefits” and “burdens” to the patient is clearer.)

**“Palliative care is integral to good health care.”**

(Because *all* patients need relief from suffering, palliative care should be accessible to all patients who need it; using this term to mean “treatment withdrawal” is confusing and creates a barrier to access.)

# Legal and Ethical Consensus (US)

**“It is ethically acceptable to provide medication sufficient to control a patient’s pain and symptoms even in the rare circumstance in which this intervention may foreseeably hasten the patient’s death.” (Rule of “double effect.”)**

**“Forgoing life-sustaining treatment is ethically and legally distinct from suicide, from euthanasia, and from physician-assisted suicide.” (Professionals should be able to explain these distinctions.)**

# Toward ethically competent care for people nearing the end of life

- Competencies for medical, clinical, and continuing education for all professionals responsible for the care of patients facing treatment decisions or nearing end of life.
- Professionals should master these aspects of practice.
- Educational institutions, teaching hospitals, professional societies should support this.

**Competency 1:**

“Maintain current knowledge of practice recommendations and research findings on life-sustaining treatment and end-of-life interventions.”

**Competency 2:**

“Learn how to integrate pain and symptom management into all treatment plans in all care settings for patients of all ages into discharge plans.”

**Competency 3:**

“Learn how to elicit patients’ treatment-related values and preferences, establish and document goals of care, and develop plans that reflect these preferences.”

**Competency 4:**

“Learn how to collaborate with patients and surrogates and work with loved ones during treatment discussions and decision-making.”

**Competency 5:**

“Learn how to collaborate with other professionals during treatment discussions and decision-making, in the process of transfer, and in discharge planning.”

**Competency 6:**

“Learn about the common causes of distress experiences by patients, surrogates, loved ones, professionals, and staff in end-of-life care settings, and how distress may affect treatment decision-making and the delivery of care.”

**Competency 7:**

“Learn how disagreements arise in decision-making about life-sustaining treatment and in care near the end of life and how to prevent and resolve conflicts with patients, among loved ones, and among professionals.”

**Competency 8:**

“Learn how to recognize legal myths about decisions concerning life-sustaining treatment and end-of-life care and take responsibility for correcting misinformation.”

**Competency 9:**

“Develop personal capacity for ethical reflection and participate in opportunities to explore ethical concerns arising in decisions about life-sustaining treatment and care near the end of life.”

# Supporting good practice in end-of-life care: reflection questions for medical educators

- Which aspects of end-of-life care make *you* feel uncertain or distressed?
- What organizational, social, legal, and/or other factors seem to contribute to these challenges?
- What do you find challenging to explain (to colleagues, students, patients, and/or families) with respect to ethics and end-of-life care?
- What do you find challenging to explain with respect to the law and end-of-life care?