

Avoiding Harm and
Improving Care Near the End of Life:
What Good Can Ethics Do?

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Leading Causes of Death (2010)

1. Heart disease
2. Cancer
3. Chronic lower respiratory diseases
4. Stroke (cerebrovascular diseases)
5. Accidents (unintentional injuries)
6. Alzheimer's disease
7. Diabetes
8. Nephritis, nephrotic syndrome, and nephrosis
9. Influenza and Pneumonia
10. Intentional self-harm (suicide)

<http://www.cdc.gov/nchs/fastats/deaths.htm>

- How does turfing introduce potential or actual harm in transitions near the end of life?
- How can we avoid turfing blame for care problems onto “difficult” patients and their “demanding,” “unreasonable,” “angry,” “crazy” (and/or “praying for a miracle”) families?
- What are some practical steps to prevent unresolved care problems from traveling with patients from shift to shift and place to place?

Two consensus reports separated by 25 years

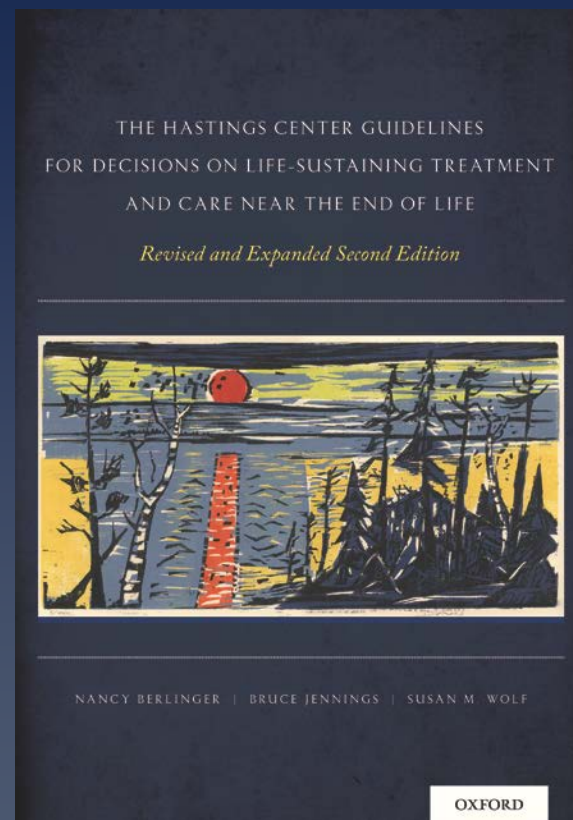
- **G1**—first ethics guidelines on EOL care (1987)
 - Formulated pre-*Cruzan*
 - Helped consolidate decision-making rights of patients & authority of surrogates
 - From theory to decision-making pathway
- **G2**—from pathway to reality of practice (2013)
 - Formulated post-*Schiavo*
 - Applying 25 years of learning
 - from “termination” of treatment to “decisions” about treatment, including chronic conditions

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 Kindle and print
from Amazon.

Companion website:
www.HastingsCenterGuidelines.org



New features in 2013 edition

- Broader scope
- Pediatrics section covering the care of infants, children, and adolescents
- Guidance reflecting perspectives of disabled patients
- Beyond autonomy to context & culture
- Practical advice on communication and collaboration
- Dedicated focus on organizations
- Evidence and insights on quality, safety, access, and cost
- Web-based resources

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.”

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Introduction:

- Function & sources of *Guidelines*
- Legal & ethical consensus

Part One: Framework & Context

Section 1: Ethics goals for good care

Section 2: Ethics education competencies

Section 3: Organizational systems

Section 4: Social, economic & legal contexts

Part Two: Guidelines on Care Planning & Decision-making

Section 1: Advance care planning & advance directives

Section 2: The decision-making process

Section 3: Neonates, infants, children & adolescents

Section 4: Care transitions (**see detail**)

Section 5: The determination of death

Section 6: Institutional policy

Contents

Part Three: Communication Supporting Decision-Making & Care

Section 1: Patients, surrogates & loved ones

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Section 4: Specific treatments and technologies

Section 5: Institutional discussion guide on resource

allocation & cost of care

Glossary

Cited Legal Authorities

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www.HastingsCenterGuidelines.org

Legal and ethical consensus

“Patients with decision-making capacity have a common law and constitutional right to refuse life-sustaining treatment.” p. 3

“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.” p. 3

“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.” p. 4

Legal and ethical consensus

“There is no ethical difference between withholding and withdrawing life-sustaining medical treatment.” p. 4

“No treatment or form of care is intrinsically ‘ordinary’ or ‘extraordinary.’” p. 4

“Palliative care is integral to good health care.” p. 5

Legal and ethical consensus

“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.” p. 5

“Forgoing life-sustaining treatment is ethically and legally distinct from suicide, from euthanasia, and from physician-assisted suicide.” p. 6

Ethics goals for good end-of-life care

- Relieve suffering
- Respect both living and dying
- Promote well-being
- Respect persons
- Respect dignity
- Respect relationships
- Respect difference
- Promote equity
- Preserve professional ethical integrity
- Use organizational systems to support good care and ethical practice

Competencies in end of life care

(Doing right by doing these things well)

- Know the outcomes data on EOL interventions.
- Integrate pain and symptom management into plans.
- Elicit patients' preferences, establish goals of care, and develop and document care plans.
- Collaborate with patients, surrogates, and loved ones.
- Collaborate with other professionals.
- Recognize common causes of distress.
- Recognize, prevent, and resolve/manage conflict.
- Recognize and correct legal myths.
- Develop capacity for personal and ethical reflection.

Using the Guidelines

Standards for Surrogate Decision-Making

Part Two, Section 2B:

“In making decisions, the surrogate should apply the following standards in this sequential order of priority:

1. **Patient’s directions:** The surrogate follows the patient’s treatment directives or other explicit preferences, written or oral.
2. **Substituted judgment:** If there are no treatment directives or other explicit preferences allowing the use of the first standard, the surrogate bases decisions on the patient’s inferred values and preferences, as best they can be gleaned from knowledge of and experience with the patient.

Using the Guidelines

Standards for Surrogate Decision-Making

Part Two, Section 2B:

3. **Best interests:** If there are no treatment directives or other explicit preferences from the patient and the surrogate lacks enough information to use the second standard, the surrogate should choose the treatment option that will be in the patient's best interests in light of the patient's condition, prognosis, and treatment options. When the patient is an incapacitated adult, this is sometimes explained as choosing what a 'reasonable person' would choose if in the patient's circumstances."

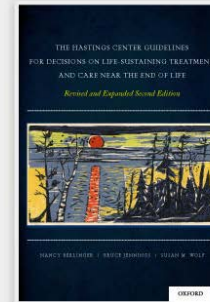
A Fresh and Timely Look at Care Near the End of Life, in a New Edition of a Classic Work

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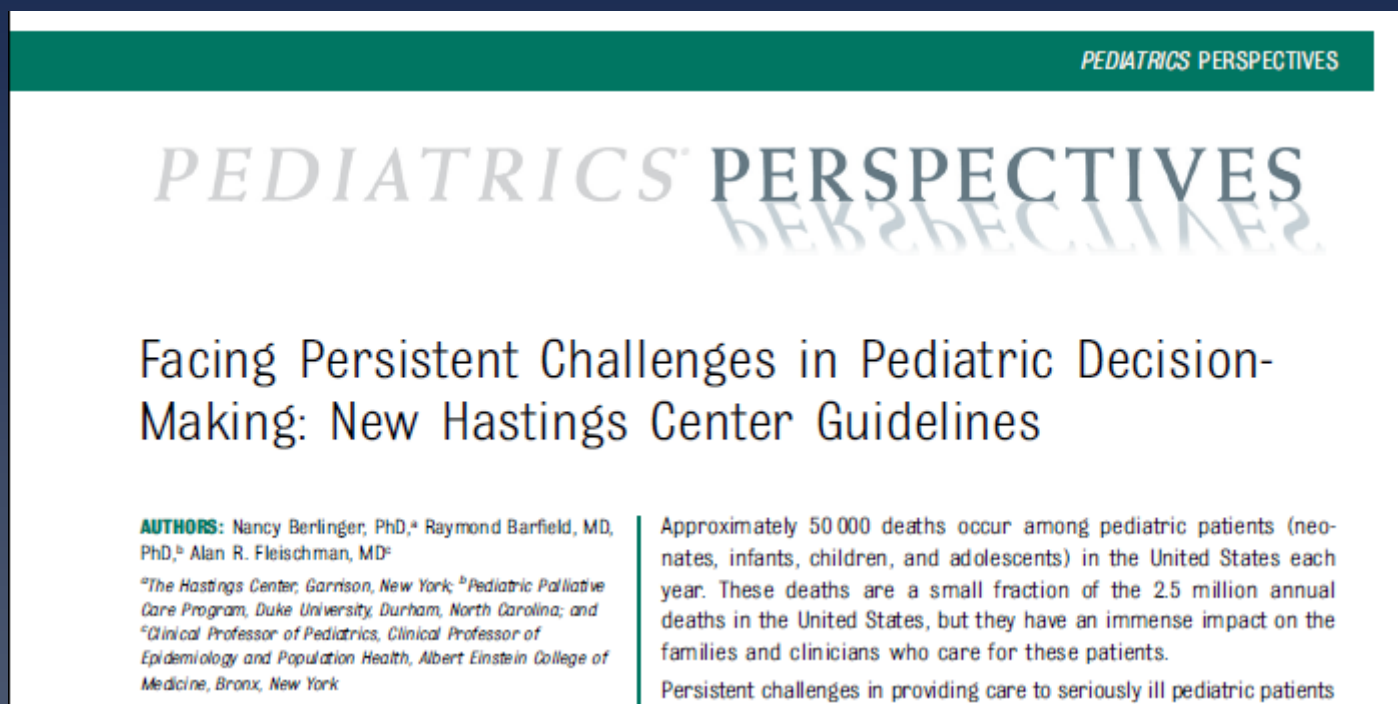
[Purchase the Guidelines](#)

This major new work updates and significantly expands The Hastings Center's 1987 *Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying*. Like its predecessor, this second edition will shape the ethical and legal framework for decision-making on treatment and end-of-life care in the United States.

This groundbreaking work incorporates 25 years of research and innovation in clinical care, law, and policy. It is written for physicians, nurses, and other health care professionals and is intended for easy reference in difficult clinical situations. It

www.HastingsCenterGuidelines.org

Facing Persistent Challenges in Pediatric Decision-Making: New Hastings Center Guidelines



PEDIATRICS PERSPECTIVES

PEDIATRICS PERSPECTIVES
GUIDELINES

Facing Persistent Challenges in Pediatric Decision-Making: New Hastings Center Guidelines

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Approximately 50 000 deaths occur among pediatric patients (neonates, infants, children, and adolescents) in the United States each year. These deaths are a small fraction of the 2.5 million annual deaths in the United States, but they have an immense impact on the families and clinicians who care for these patients.

Persistent challenges in providing care to seriously ill pediatric patients

N Berlinger, R Barfield, and AR Fleischman, “Facing Persistent Challenges in Pediatric Decision-Making: New Hastings Center Guidelines,” *Pediatrics* published online: October 7, 2013; (doi: 10.1542/peds.2013-1378)