

THE HASTINGS CENTER GUIDELINES

*for Decisions on Life-Sustaining
Treatment and Care Near the End of Life*

Revised and Expanded Second Edition
by Nancy Berlinger, Bruce Jennings, and Susan M. Wolf
Oxford University Press, 2013 (print and e-book)

Improving care near the end of life is profoundly difficult.

There has been progress. Landmark court cases, such as those of Karen Ann Quinlan (1976) and Nancy Cruzan (1990), established the constitutional and common-law rights of patients to refuse life-sustaining treatment and recognized the authority of surrogate decision-makers for patients who lack decision-making capacity. Public policy, including the Patient Self-Determination Act (1990), supported the development of advance directives to document instructions for future care. The grassroots hospice movement and the creation of the Medicare hospice benefit (1982) created an alternative model of care for dying patients. Research and education on end-of-life care expanded, leading to initiatives in advance care planning to guide future care and in better treatment of pain and symptoms through palliative care. Bioethics scholarship on the nature of suffering sharpened our understanding of medicine's responsibilities to the patient as a person.

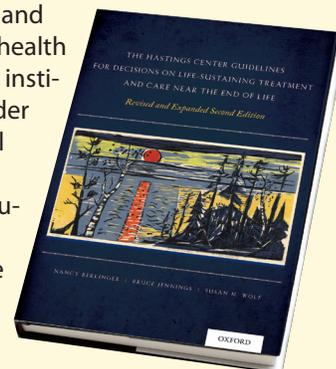
In the past decade, new issues have emerged and continuing challenges have resurfaced. Conflict within the family of Terri Schiavo, a young woman in a permanent vegetative state, erupted into a national debate, revealing the complexity of surrogate decision-making and unresolved challenges in how we communicate about diagnosis and prognosis. The run-up to the Affordable Care Act of 2010 saw political controversy over proposed coverage for advance care planning, but the health reform law succeeded in improving hospice access for children. Debates and policymaking about physician-assisted suicide continue. As health care reform is implemented in the years ahead, structural changes to end-of-life care are inevitable.

Access to advance care planning and to the integration of palliative care into health care are works in progress. Research into the psychology of making decisions for oneself and others, and on the neurodevelopment of decision-making capacity in children and adolescents, continues to reveal the complexity of making decisions about life-sustaining treatment and suggest the need for better ways to support patients, surrogates, and loved ones. New treatments for some life-threatening conditions mean that some patients will make treatment decisions and live with chronic conditions over years or decades.

New Features in the Second Edition

- broader scope, which includes advance care planning, chronic illness, and decision-making about starting, continuing, or forgoing treatment and end-of-life care
- pediatrics section covering the care of infants, children, and adolescents
- guidance reflecting the perspectives of disabled patients
- practical advice on communication and collaboration
- evidence and insights on quality, safety, access, and cost
- Web-based resources

Ethics guidelines are based on established ethical and legal consensus about standards of care, individual rights, and the responsibilities of health care professionals and institutions. They are broader than technical medical guidelines or legal advice. They support accurate knowledge of law and policy and the use of evidence-based practice guidelines.



Decisions about life-sustaining treatment remain difficult decisions. Coping with suffering, facing death, and providing good care when a person is nearing the end of life, are difficult experiences. No person, no family, no community, can avoid these decisions and experiences, because they are part of human life. Talking about these issues is also challenging, whether or not a person knows what he or she wants.

As our country implements health care reform and confronts the needs of an aging population living with chronic conditions, the burdens and benefits of new treatments and technologies, and cost implications, it is time for a fresh look at care near the end of life.

About The Hastings Center Guidelines

In 1987, The Hastings Center published the first set of ethics guidelines to help physicians, nurses, and other health care professionals provide good care under difficult circumstances.

The Hastings Center Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying was a groundbreaking book that was widely consulted and influential both in the United States and internationally. It was cited in the U. S. Supreme Court's Cruzan decision, which established the Constitutional right to refuse medical treatment. It helped shape the ethical and legal framework for medical decision-making and end-of-life care we rely on today.

The Hastings Center has revised and greatly expanded this essential resource to reflect the past 26 years of research and innovation from the quality improvement, patient safety, and palliative care movements, with insights from more than 60 experts in medicine, law, nursing, and other disciplines, from the disability community, and from patient advocates.

- The *Guidelines* are structured for easy reference in difficult clinical situations.
- Searchable e-book format allows users to quickly locate material of interest.
- Sections of the book can be used as teaching tools.
- Bibliography includes Web-based resources to use in practice and share with patients and families.
- The *Guidelines* Web site (www.hastingscenterguidelines.org) is free and public and offers additional resources.

What's in the new Guidelines

The Introduction describes the current ethical and legal consensus around treatment decision-making in the U.S., helping professionals avoid common errors when discussing these topics. It presents a valuable summary of rights, protections, and key distinctions. It offers clear descriptions of key ideas in end-of-life care, such as the right to refuse life-sustaining medical treatment, the authority of surrogate decision-makers, and the decision-making standards they should follow. The Introduction also describes current state laws and policies permitting physician-assisted suicide under certain conditions, and how this practice is distinct from treatment refusal and from palliative care.

PART ONE

provides a framework for health care professionals, educators, and organizations. It features ethics goals for good care when patients face decisions about life-sustaining treatment or approach the end of life; educational competencies for health care professionals involved in the care of these patients; descriptions of the organizational systems supporting good care and ethical practice; and the social, economic, and legal context of treatment decision-making and end-of-life care, with attention to state and federal law and policy.

PART TWO

offers extensive practical guidance. It features:

- **Guidelines for Advance Care Planning and Advance Directives**

Gives recommendations on advance care planning with patients planning for future care, and on the use of patient preferences to establish goals of care and develop care plans. Clearly explains different types of advance directives and advance care planning processes.

- **Guidelines for the Decision-Making Process**

Covers the clinical evaluation and determination of decision-making capacity. Gives detailed guidance on all aspects of surrogate decision-making, including the use of the three-tiered standard (patient's instructions, substituted judgment, best interests) when a patient lacks decision-making capacity. Explains how to make, document, implement, and change treatment decisions, and how to manage different types of challenges and conflicts in decision-making.

- **Guidelines Concerning Neonates, Infants, Children, and Adolescents**

Addresses special considerations in making decisions in pediatric settings. Describes the application of the best-interests standard when children are unable to participate in decision-making due to age or health condition, and the involvement of the developing child and the adolescent in decision-making. Provides specific guidelines for perinatal, neonatal, pediatric, and adolescent patients and for decision-making involving foster children, mature minors, and emancipated minors.

- **Guidelines for Care Transitions**

Supports care coordination during hand-offs, transfers, discharge planning, and in the creation and use of portable medical orders. Discusses how to prevent common problems in the care of frail elderly nursing home residents and of patients who will die in the hospital.

- **Guidelines for the Determination of Death**

Gives procedural guidance in accordance with current legal and clinical consensus for making a determination of death and a declaration of death using cardiopulmonary and neurological criteria. Explores how to manage religious and other accommodations and objections to a determination of death. Explains the current debates over organ donation after cardiac death, to support attention to clinician education and clear communication on this topic.

- **Guidelines for Institutional Policy**

Provides guidance for developing organizational policy and processes to support good care at the bedside, clear communication among health care professionals, and the resolution of care problems. Offers concrete recommendations for policy on ethics consultation, ethics committees, palliative care services, advance care planning, use of portable medical orders, care transitions, and conflict resolution. Describes how health care lawyers and risk managers can support ethics by correcting myths about law and liability.

PART THREE

provides in-depth guidance on communication supporting decision-making and care. It features:

- **Communication with Patients, Surrogates, and Loved Ones**

Includes a model process for conducting a family conference. Provides additional guidance on dealing with common challenges, such as supporting a decision-maker during a family conflict or talking about nutrition and hydration when a patient is nearing the end of life.

- **Communication and Collaboration with Patients with Disabilities**

Developed with extensive input from persons living with disabilities and from other experts in disability, this section gives practical recommendations on communication when a patient's disability affects speech or cognition or is of recent onset. Insights on caring for people who use life-sustaining treatment to accommodate stable or progressive conditions are also provided.

- **Psychological Dimensions of Decision-Making**

Concise descriptions clarify how psychological factors, including coping practices, hope, ambivalence,

denial, grief, bereavement, existential suffering, spiritual and religious concerns, and moral distress, can be acknowledged and addressed when treatment and care decisions are being made. Offers guidance on understanding and managing religious objections during treatment decision-making.

- **Decision-Making Concerning Specific Treatments and Technologies**

This section describes ethical and practical considerations for clinicians when patients forgo life-sustaining treatments. Definitions and recommendations are given for communicating with surrogates, loved ones, and colleagues about a range of specific topics, including brain injuries and neurological states, mechanical ventilation, CPR and cardiac treatments, dialysis, nutrition and hydration, cancer treatments, routine medications, antibiotics, invasive procedures, blood transfusion and blood products, and palliative sedation. Emerging issues and areas of debate are discussed.

- **Institutional Discussion Guide on Resource Allocation and the Cost of Care**

Offers six strategies to support productive discussion and informed policymaking on these topics.

The *Guidelines* also include a Glossary, a list of Cited Legal Authorities, a 500-item Selected Bibliography of print and Web resources, and an Index.

About the Authors

- **Nancy Berlinger** is a Research Scholar at The Hastings Center and teaches ethics at the Yale University School of Nursing. She directed The Hastings Center project that produced the revised and expanded second edition of the *Guidelines*.

- **Bruce Jennings** is Director of Bioethics at the Center for Humans and Nature and teaches ethics at the Yale University School of Medicine. He is an elected Fellow of The Hastings Center and was a co-author of the first edition of the *Guidelines* in 1987.

- **Susan M. Wolf** is McKnight Presidential Professor of Law, Medicine & Public Policy at the University of Minnesota and a Faculty Member in the University's Center for Bioethics. She is an elected Member of the National Academy of Science's Institute of Medicine, elected Fellow of the AAAS, and elected Fellow of The Hastings Center. She directed The Hastings Center project that produced the first edition of the *Guidelines* in 1987, and was principal author of that work.

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