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# Report from the Field

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## Approaching Death: Improving Care at the End of Life—A Report of the Institute of Medicine

Both society and individuals often fall short of providing humane care—effective, reliable, compassionate care—at the end of life. Many people have, in turn, come both to fear a technologically overtreated and protracted death and to dread the prospect of abandonment and untreated physical and emotional distress. They lack trust that the healthcare system will help them achieve a decent or good death—one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.

This Institute of Medicine report stresses several themes that reflect the broad deficiencies that exist in the care of people with life-threatening, incurable illnesses:

- Too many dying people suffer from pain and other distress that clinicians could prevent or relieve with existing knowledge and therapies.
- Significant organizational, economic, legal, and educational impediments to good care can be identified and, in varying degrees, remedied. Outdated and scientifically flawed drug-prescribing laws, regulations, and interpretations by state medical boards continue to frustrate and intimidate physicians who wish to relieve their patients' pain.
- Important gaps in scientific knowledge about the end of life need serious attention from biomedical, social science, and health services researchers.
- The education and training of physicians and other healthcare professionals fail to provide them the attitudes, knowledge, and skills required to care well for dying patients.
- Strengthening accountability for quality of care at the end of life will require better data and tools for evaluating the outcomes important to patients and families.

The report contains seven recommendations aimed at addressing and remedying these shortcomings:

1. *People with advanced, potentially fatal illnesses and those close to them should be able to expect and receive reliable, skillful, and supportive care.* Educating people about care at the end of life is a critical responsibility of physicians, hospitals, hospices, support groups, public programs, and media.

2. *Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms.* Practitioners must hold themselves responsible for assessing, preventing, and relieving physical and emotional distress.

3. *Because many problems in care stem from system problems, policymakers, consumer groups, and purchasers of healthcare should work with healthcare practitioners, organizations, and researchers to* (a) strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them; (b) develop better tools and strategies for improving the quality of care and holding healthcare organizations accountable for care at the end of life; (c) revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care; and (d) reform drug prescription laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering.

4. *Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients.* Dying is too important a part of life to be left to one or two required (but poorly attended) lectures, to be considered only in ethical and not clinical terms, or to be set aside on the grounds that medical educators are already swamped with competing demands for time and resources.

5. *Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research.* The objective is to create a cadre of palliative care experts to (a) provide expert clinical consultation and role models for colleagues, students, and other members of the healthcare team; (b) supply educational leadership; and (c) organize and conduct research. More generally, palliative care must be redefined to include prevention as well as relief of symptoms.

6. *The nation's research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care.* Priorities are health services research that explores goals important to dying patients, measures the extent

to which such goals are achieved, and identifies factors contributing to or impeding effective and compassionate care at the end of life.

7. *A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death.* Individual conversations between practitioners and patients are important but cannot by themselves provide a more supportive environment for the attitudes and actions that make it possible for most people to die free from avoidable distress and to find the peace or meaning that is significant to them.

*Approaching Death: Improving Care at the End of Life* is available for sale from the National Academy Press, 2101 Constitution Avenue, N.W., Box 285, Washington, DC 20055. Call 800/624-6242 or 202/334-3313 (in the Washington metropolitan area), or visit the NAP's online bookstore at [www.nap.edu/bookstore](http://www.nap.edu/bookstore).

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