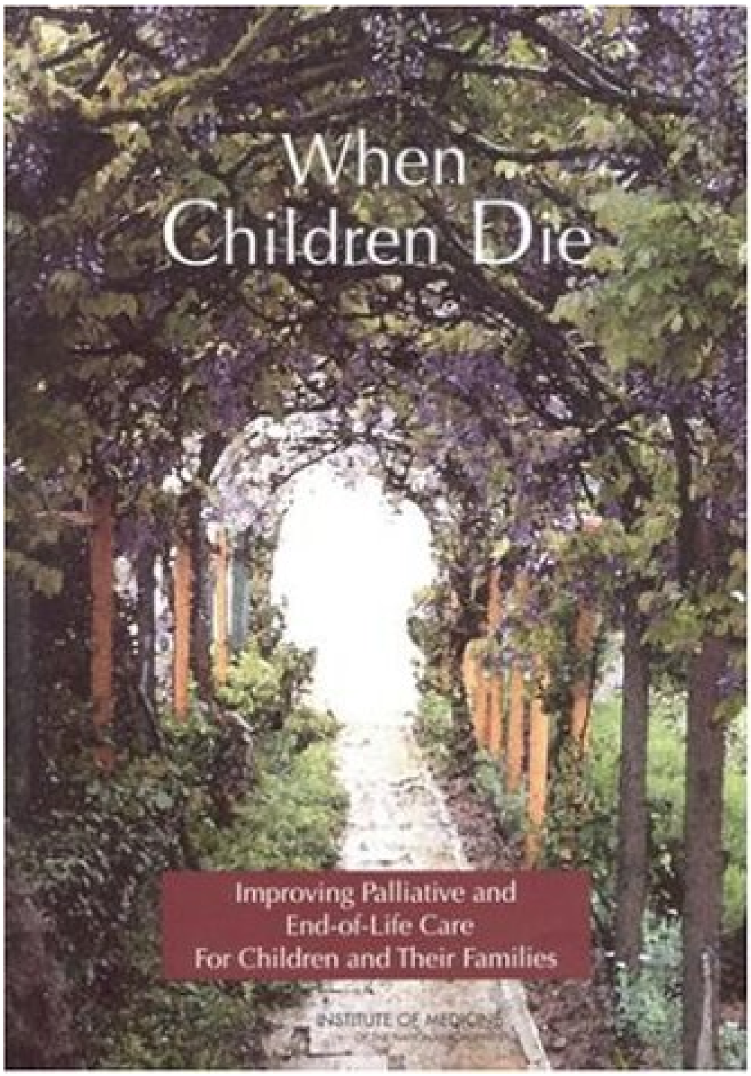
# When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families--Summary

*Institute of Medicine, Board on Health Sciences Policy, Committee on Palliative and End of Life Care for Children and Their Families*



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**Institute of Medicine, Board on Health Sciences Policy, Committee on Palliative and End of Life Care for Children and Their Families : When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families--Summary** before purchasing it in order to gage whether or not it would be worth my time, and all praised When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families--Summary:

5 of 6 people found the following review helpful. Confusing informationBy Rebecca J. SeloveThere are two publications with the same name, same publisher, same publication year. One is referred to as a paperback, and costs $12, while the other is referred to as hardcover, and costs $45. It is not clear from the description of these two documents how different they are - the paperback is actually a pamphlet, about 12 pages, a summary of the other, a several hundred page book. Choose which you want based on this information.

This document is a brief summary of the Institute of Medicine report entitled When Children Die: Improving Palliative and End-of-Life Care for Children. Better care is possible now, but current methods of organizing and financing palliative, end-of-life, and bereavement care complicate the provision and coordination of services to help children and families and sometimes require families to choose between curative or life-prolonging care and palliative services, in particular, hospice care. Inadequate data and scientific knowledge impede efforts to deliver effective care, educate professionals to provide such care, and design supportive public policies. Integrating effective palliative care from the time a child's life-threatening medical problem is diagnosed will improve care for children who survive as well as children who die-and will help the families of all these children. The report recognizes that while much can be done now to support children and families, much more needs to be learned. The analysis and recommendations reflect current knowledge and judgments, but new research and insights will undoubtedly suggest modifications and shifts in emphasis in future years.

From The New England Journal of MedicineThe death of a child holds such sadness for many health care professionals that they will have trouble bringing themselves to read a book that so openly considers this tragedy. Yet it is critical that those same professionals delve into this book. Within its pages they will find documentation of the experiences that children with life-threatening illnesses have in the U.S. health care system. They will receive guidance on ways to improve the care of these children and will be inspired by ideas for future research. When Children Die stands as a testament to the commitment made by the Institute of Medicine to explore and publicize end-of-life issues in health care. Its first two reports in this field dealt with the experiences of adults, but in 1999 the institute's Board on Health Sciences Policy recommended an investigation of the care of dying children and their families. The institute convened a committee of 14 experts to oversee the study and secured funding from a variety of public and private sources. The ambitious goals of the committee members were to develop a report that, in their words, described the major causes and settings of death for children; reviewed what is known about 1) the medical and other services provided to dying children and their families and 2) the education of physicians and other professionals who care for gravely ill children; assessed the state of knowledge about clinical, behavioral, cultural, organizational, legal, and other important aspects of palliative and end-of-life care for children and their families; examined methods for communicating information, determining family and child/patient preferences, resolving conflicts, and evaluating the quality of palliative and end-of-life care as experienced by children and their families; and proposed a research and action agenda to strengthen the scope and application of the knowledge base for providing effective and compassionate care for children who die and their families. This book documents and summarizes the answers committee members received from their own experience and research and from others they consulted. These responses include a series of commissioned background articles (available online as appendixes) and information gathered at public meetings of parent and professional groups. The committee also heard directly from parents about their experiences caring for a dying child. The report succeeds in documenting both the scientific and the personal challenges involved in caring for children who die. Relevant quotations from dying children, their parents, and their siblings highlight the importance of topics ranging from communication and goal setting to financial, legal, and ethical issues. This report is not meant to be a clinical textbook, so the chapter entitled "Care and Caring from Diagnosis through Death and Bereavement" includes a descriptive outline of common physical symptoms encountered in dying children, but it offers no treatment guidelines. Similarly, the discussion of educating health care professionals features goals and models for teaching palliative care, but not the specific content of such education. Throughout the book, the committee delineates action imperatives based on its assessment of needs and current reality. An example of the specificity of the recommendations is that public and private insurers should restructure hospice benefits, allowing hospice teams to care for children on the basis of diagnosis rather than prognosis, even when a child is receiving potentially curative or life-prolonging therapy. The committee advocates early involvement of an interdisciplinary team to help families set goals for care and to coordinate care across home and clinic and hospital settings. The way a society treats its children mirrors its successes and its failures. This book argues that it is imperative that knowledgeable physicians and nurses assess and treat pain in nonverbal infants. Is it any less important to treat pain in nonverbal elderly persons who have Alzheimer's disease? It emphasizes the importance of supporting the parents of a 4-year-old child with cancer, but is it any less critical to care for the children of a 40-year-old adult with cancer? It also criticizes a health care system in which 15 to 26 percent of children have no insurance coverage, leaving families at risk for financial devastation if serious illness occurs. Yet is it less wrong when an elderly person's savings are wiped out because of a life-threatening condition? In many ways, improving the care of dying children in this country could have a substantially positive effect on the care of dying adults. When Children Die advocates the type of whole-person, whole-family care that many crave as they near life's end. Its recommendations could lead the way to better care, not only for affected children and their families, but for all who must deal with life-threatening illnesses. Kate W. Faulkner, M.D. About the AuthorMarilyn J. Field and Richard E. Behrman, Editors, Committee on Palliative and End-of-Life Care for Children and Their Families