



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

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

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The death of a child is a special sorrow. No matter the circumstances, a child's death is a life-altering experience. Except for the child who dies suddenly and without forewarning, physicians, nurses, and other medical personnel usually play a central role in the lives of children who die and their families. At best, these professionals will exemplify "medicine with a heart." At worst, families' encounters with the health care system will leave them with enduring painful memories, anger, and regrets.

When Children Die examines what we know about the needs of these children and their families, the extent to which such needs are—and are not—being met, and what can be done to provide more competent, compassionate, and consistent care. The book offers recommendations for involving child patients in treatment decisions, communicating with parents, strengthening the organization and delivery of services, developing support programs for bereaved families, improving public and private insurance, training health professionals, and more. It argues that taking these steps will improve the care of children who survive as well as those who do not—and will likewise help all families who suffer with their seriously ill or injured child.

Featuring illustrative case histories, the book discusses patterns of childhood death and explores the basic elements of physical, emotional, spiritual, and practical care for children and families experiencing a child's life-threatening illness or injury.

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