



When Treatment Fails: How Medicine Cares for Dying Children

By David J. Bearison

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Medical care of the terminally ill is one of the most emotionally fraught and controversial issues before the public today. As medicine advances and technologies develop, end-of-life care becomes more individualized and uncertain, guided less by science and more by values and beliefs. The crux of the controversy is when to withhold or withdraw curative treatments--when is enough, enough?

Political debates rage about when treatment is no longer effective; difficult cases are contested in courts; and the media devour the most sensational aspects of end-of-life care. In all this excitement and controversy, what is sadly overlooked is the extreme pressure that care of the terminally ill puts on medical staff as they deal with patients and their families and make life-or-death decisions. That pressure--the psychological strain and continuing uncertainties--is magnified when the patients are children.

David Bearison looks at this controversial issue from the perspective of the medical staff caring for dying children. Not just doctors, but nurses and counselors as well. By capturing their stories--as no other book has, Bearison is able to move beyond broad, abstract ideas about end-of-life care to convey the situated contexts of such care, including the complications, disagreements, frustrations, confusions, and unexpected setbacks.

In addition to a discussion of questions surrounding whether to withhold or withdraw curative treatments, *When Treatment Fails* explores the crucial concerns of those medical practitioners who care for dying children: education and training, relation with one another, communicating with patients and families, and finally, coping and moving on. Ultimately, the threads connecting these themes are the great costs and rewards of this difficult work, and the lessons that can be drawn from the nitty-gritty experiences of medical practitioners who struggle to find the balance between trying to defeat death and trying to provide comfort.



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Editorial Review

Review

"This is a deeply moving, yet masterfully organized book about children dying of fatal diseases--the impact of death on parents, doctors, and nurses. If death is the 'looming terror' of life, a child's death multiplies the terror and attendant sense of loss. There is no 'theory of death,' and Professor Bearison wisely uses narrative accounts to capture the uniqueness of each death and its human impact. What eases the suffering is humane and honest communication between parents and dying kids, but also between parents and medical staff. But as Jessica Mitford once put it, 'Gracious dying is a huge, macabre, and expensive joke on the American people.' This book is required reading for those concerned with the 'management' of the tragic."--Jerome Bruner, University Professor, New York University

"Bearison takes us directly to the bedside of seriously ill and dying children, into the hearts and minds of their parents, and into the struggle to know--and then to do--the right thing as experienced by their nurses and doctors. These stories are the truths behind the miracles of modern medicine from the point of view of its practitioners--truths about the rebirth of hope with each new patient, about the cost of repeatedly witnessing suffering in children and their parents, about how hard it is to stay close enough to remain human but far enough to retain professional boundaries, about guilt and grief and loss when treatment fails, and then about having to get up the next day and do it all over again."--Diane Meier, Director, Lillian and Benjamin Hertzberg Palliative Care Institute; Director, Center to Advance Palliative Care; Catherine Gaisman Professor of Medical Ethics; and Professor, Departments of Geriatrics and Medicine, Mount Sinai School of Medicine

"In presenting clinician narratives, Dr. Bearison succeeds in going well beyond the usual 'sound bite' to give voice to the complexity, challenge, and drama of providing care at the end of life for children and their families. The narratives spare no detail and no emotion. Clinicians of all disciplines and varying levels of experience working with dying children owe it to themselves to read this book. The stories, struggles, strategies, language, ways of coping, and insights revealed by these fellow clinicians are a gift, and one that can teach and guide us all."--Elaine C. Meyer, Ph.D., R.N., Director, Program to Enhance Relational and Communication Skills, Children's Hospital Boston, and Assistant Professor of Psychology, Department of Psychiatry, Harvard Medical School

"The new book seeks to explore previously uncharted territory: the inner workings of physicians' minds as they wrestle with the deteriorating health--and approaching death--of very ill young patients."--*Folio*

"This book is truly unique in its evaluation of pediatric end-of-life care issues from the medical staff's perspective. It is of high quality and would be useful reading for all medical personnel involved in the care of a dying child."--*Doody's*

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"...rich, searingly honest, self-disclosing, compelling, occasionally harrowing, and always thought-provoking. There are some beautiful and moving statements, especially from nurses, and some marvelous words of wisdom from attending physicians...It is the dispassionate reporting of the sheer complexity of conflicting issues, aspirations, and judgments about what is considered best for a particular patient and family in a particular situation that will ensure the lasting value of this book, particularly as a resource for discussion, workshops, and team-building within pediatric hematology / oncology units."--Michael M. Stevens, Fellow, Royal Australasian College of Physicians (Pediatrics), Senior Staff Specialist and Attending, Oncology Unit, The Children's Hospital at Westmead in Sydney, Australia

"This is a wonderful book written in a unique style. The author has managed to capture, by using actual events, the essence of the problems facing those who are taking care of children for whom treatments have failed and are slowly dying. I can't remember ever reading a book on this subject, which contains so much clear thinking, wisdom and no jargon!...[T]his book is really one that all young physicians in training should be required to read. Actually, it needn't be required as I predict that if you read a few pages, you would realize what a great book it is."--*Pediatrics*

"The book offers a remarkable treasure trove of lived experiences of clinicians from which novice and seasoned clinicians may learn and deepen their insight about end-of-life care of children."--*JAMA*

About the Author

David J. Bearison's many positions include Professor of Developmental Psychology at the Graduate Center of the City University of New York, Adjunct Professor of Medical Psychology in Pediatrics and Psychiatry at the College of Physician and Surgeons of Columbia University, and Attending at the Children's Hospital of New York (CHONY), Columbia Presbyterian Medical Center. He is a member of the American Psychological Association's Task Force on End-of-Life Issues for Children and Adolescents. He lives with his wife, a pediatric oncologist, in New York City and Croton on Hudson, NY.

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