

The Edge of Medicine: Stories of Dying Children and Their Parents

David J. Bearison



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Pediatric end-of-life care raises exceedingly difficult questions: Is there a natural trajectory for children to die in hospitals or at home? How might we, in developmentally appropriate ways, involve children in end-of-life decisions?

While there is no "correct" way to die, David Bearison concludes that all end-of-life issues in pediatrics boil down to finding ways to respect and honor what patients, under the purview of their families, find is best for them. This issue is conceptually simple, but practically complex, as Dr. Bearison highlights in The Edge of Medicine. The book tells the stories of dying children and their families, capturing the full range of uncertainties, hopes and disappointments, and ups and downs of children near the end of life. The Edge of Medicine serves as the perfect follow-up to David Bearison's When Treatment Fails: How Medicine Cares for Dying Children, which is based on the narratives of hospital staff caring for dying children (and their families). Together with its prequel, The Edge of Medicine presents a more complete picture of what happens when everyone involved, from medical staff to patients and their families, is struggling with pediatric end-of-life care. Dr. Bearison relies on narrative to bridge the disconnect among abstract theories, medical technologies, and clinical realities.

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