



# Shelter From The Storm: Caring For A Child With A Life-threatening Condition

*Joanne Hilden, Daniel Tobin, Karen Lindsey*

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critically ill and unlikely to survive. A recent Harvard University study on pediatric end-of-life care has shown that the medical community is failing such children and their families. Indeed, in their effort to be ever-hopeful and cure-oriented in the face of a child's terminal illness, they neglect to advise parents on the basics of emotional support for all family members, pediatric pain medication, and the need for making plans and worst-case preparations. Based on the National Advanced Illness Coordinated Care program and the stories and advice gleaned from co-author Joanne Hilden's years of work as a pediatric oncologist, *Shelter from the Storm* fills this advice-and-caregiving void. A compassionate road map to what the family may have to face, what they may be asked to decide, and how they might want to involve their child in the decision-making, *Shelter from the Storm* will help parents and caregivers make informed, loving, and protective choices on behalf of their children in the most trying of times.

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