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BOOK REVIEW

When Your Child is Sick: A Guide to Navigating the Practical and Emotional Challenges of Caring for a Child Who is Very Ill

By Joanna Breyer. 448 pp. New York: TarcherPerigee an Imprint of Penguin Random House LLC., 2018. Paperback $16.00, ISBN 9780147517586

In "When Your Child is Sick," Joanna Breyer offers the reader a field guide of sorts in navigating the often precarious and emotionally challenging landscape inherent to caring for a child with serious illness. From her unique perspective as a clinical psychologist with decades of experience in working with pediatric oncology patients and their families at the Dana Farber Cancer Institute, she further extrapolates her viewpoint beyond the scope of childhood cancer. In doing so, she aptly addresses universal themes relevant to children "hospitalized for a variety of reasons, such as a sudden severe injury or chronic conditions such as cystic fibrosis, sickle cell anemia, diabetes, or chronic cardiac complications" (page x).

At the outset, her comprehensive treatise first lays out a framework to demystify the labyrinthine hospital environment and its key players. She outlines exceedingly practical methods for caregivers themselves to cope with the initial shock of an inpatient hospitalization insofar as optimizing their own physical, emotional, mental, spiritual, and financial wellbeing while also strongly advocating for their child's best interests. She then provides specific and age-appropriate methods for communicating with children about their illness while taking their developmental maturity and personality into account. Importantly, she explicitly acknowledges that while each child's experience remains unique to that particular patient's challenges, there are certain universal principles such as uncertainty, fear, and overwhelm that most caregivers will inevitably grapple with.

Interwoven throughout her narrative, Dr. Breyer provides the reader with vignettes highlighting real-world examples taken from her own experience as a psychologist working with children and their families. In doing so, she firmly grounds her theoretical principles in the oft-stark reality of the patient experience and offers her readers a glimpse inside real patient encounters. When describing useful coping techniques for hospitalized children, she explains the benefits of medical play in allowing "the child to express feelings, to absorb difficult experiences by acting them out over and over again, to try out new ideas, to take on different roles (the child becomes the aggressor instead of the victim, the big guy instead of the little guy)" (page 50). She then beautifully describes how medical play transformed the experience of a young boy named James who was diagnosed with cancer at 3 years of age. James endured multiple invasive medical procedures during a 6-week stay in the pediatric intensive care unit and subsequently arrived on the general oncology unit withdrawn, anxious, and refusing to eat or play. Dr. Breyer then gradually introduced James to a stuffed puppet monkey named Charlie, who enabled James to feel less alone during his treatments and have his worries and fears named by someone else. Through identification with the puppet, James was able to express his feelings through Charlie, thus making his experiences in the hospital more familiar and less daunting. This simple yet effective suggestion is made all the more accessible to the reader through the use of a chart that outlines specific examples of dialog for caregivers to use when introducing a puppet to a young child during medical play (page 51). Using simple and clear language throughout the guide, Dr. Breyer first describes a concept in detail (e.g., utilizing distraction and affirmations, taking medications, enduring painful procedures, navigating a stem cell transplant). She then skillfully deconstructs each topic into actionable steps that parents can employ, making overwhelming ideas more manageable and user friendly.

Clearly, “When Your Child is Sick” serves as a valuable guide for parents and other caregivers newly charged with the difficult task of attending to a seriously ill child. The third section of Dr. Breyer’s book, “When Your Child’s Treatment Does Not Work,” provides gentle yet compelling advice for those families whose children endure irreversible or incurable conditions. While she allows for a range of emotional reactions and a multiplicity of viewpoints within the individual, Dr. Breyer provides useful anticipatory guidance for parents in this situation to grapple with the idea of their child’s death and start early advanced care planning when possible. In doing so, the book empowers parents, but also provides key insights for pediatric healthcare providers from all disciplines to act and speak from a more compassionate and humanistic vantage point.

On a personal note, my work as a pediatric palliative care physician seeks to ease suffering and improve quality of life for seriously ill children from a holistic (medical, psychosocial, and spiritual) perspective. My team supports these particularly vulnerable children, families, and their primary healthcare teams in complex medical decision-making and advanced care planning, easing pain and refractory symptoms, coordinating home care efforts, and addressing any specific issues pertinent to our families. Thus, we routinely use many of the techniques described in Dr. Breyer’s guide as it pertains to the care of our patients by equipping their families with the information required to support them more effectively. While the book touches on the idea of palliative care briefly, it does not explicitly describe the pivotal role of an inpatient, multi-disciplinary palliative care team (consisting of physicians, nurses, social workers, chaplains, child life therapists, and psychologists, among others) in providing an additional layer of support to hospitalized children and families dealing with the stress of serious illness. In my view, it also misses a critical opportunity to dispel the myth that palliative care is synonymous with hospice care and only reserved for those children who are actively dying. Rather, our discipline serves seriously ill children regardless of their age, diagnosis, or prognosis. Indeed, the parents and caregivers whom this book is designed to help would benefit from a more thorough understanding of palliative care as yet another helpful resource available to them. Apart from this small limitation, any parent or caregiver of a child dealing with a life-altering condition would find this guide an invaluable resource in traversing the trials of serious pediatric illness.

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