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Book gives siblings of ill kids some much-needed attention

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By Jason Millman, USA TODAY

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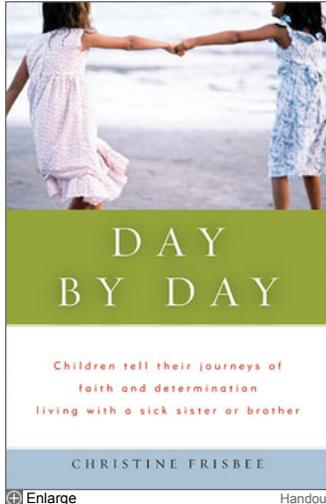
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This book compiles diary entries from children with seriously ill siblings.

On this Siblings Day, recognized in 40 states today, Christine Frisbee of New York City wants people to remember what she calls the "forgotten siblings" — the brothers and sisters of chronically ill children.

Frisbee's teenage son, Rich, died in 1989. He had leukemia. In the almost 12 months from the diagnosis to Rich's death, Christine and her husband, Rick, the parents of five children, shuttled back and forth to the hospital each day. And in the hectic life of a parent with a seriously ill child, Frisbee realized she made little time for her other children, who, just like other children, needed their parents.

"Nobody teaches you how to live with a sick child," Frisbee says. "That's learned on the spot. It's very, very hard as a mother to feel inadequate."

'You feel so guilty'

Almost 20 years after her son's death, Frisbee is now the author of *Day by Day*, a book being released later this month that compiles diary entries from children with seriously ill siblings. Reading through the entries of the book, published by the Richard D. Frisbee III Foundation, one thing becomes clear: As families try to cope with the illness, the healthy children feel as if they have become an afterthought to their parents.

Frisbee remembers the long days at the hospital with her dying son. Little else mattered to her, and looking back now, she regrets not giving more attention to her other children. "It seemed like there was so often these little crises going on, and you feel so guilty that you couldn't be there for them."

Children with a sick sibling come to realize that the illness forces their parents to prioritize their lives around helping the ailing child, says Gerald Koocher, a pediatric psychologist and dean of the School for Health Studies at Simmons College in Boston.

"Obviously, families do their best under awful circumstances, but especially if the healthy kid is doing OK, they're not the squeaky wheel," he says. Though it is natural for healthy children to harbor resentment for the sick sibling who receives more attention, they rarely voice their emotions to their parents, Koocher says.

"How can you say to your parents without feeling selfish, 'I need something more for you when you're taking care of my sibling who can't do the things I can do or is chronically ill.' "

'Queen' in the hospital

Frisbee's daughter, Meg, who at age 7 donated bone marrow to her brother, said at the time that she never thought about whether the procedure would save his life. After watching her parents devote every waking hour to Rich, Meg was thrilled to finally have the spotlight back on her.

"I was so excited to be in that role and have people fawn over me. I would be dramatic and 'need' a wheelchair, though I was perfectly fine to walk," says Meg, now 26, who contributed to her mother's book a diary entry that she wrote at 14. "I got to be in the hospital and be queen for a week."

The 7-year-old Meg was angry with her brother because he got all the attention. But then she also felt guilty and selfish about her anger. She knew she was supposed to be good for her parents, who were already going through so much.

Mallory Stratton, 15, who wrote about dealing with her brother's autism, said she used to be angry that her parents were more accommodating to her brother.

"They always used to tell me, 'The world doesn't revolve around you,' yet at the same time, our world was revolving around my brother, and I saw that as very unfair," says the teenager from Orange, Conn.

Frisbee says she hopes her book, which benefits the foundation created in her son's memory that raises money for cancer research, will provide insight into the daily struggles the siblings face.

"We need to have a greater awareness that the siblings need attention and need to verbalize what they're feeling," she says. "I hope people understand what these children are going through."

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