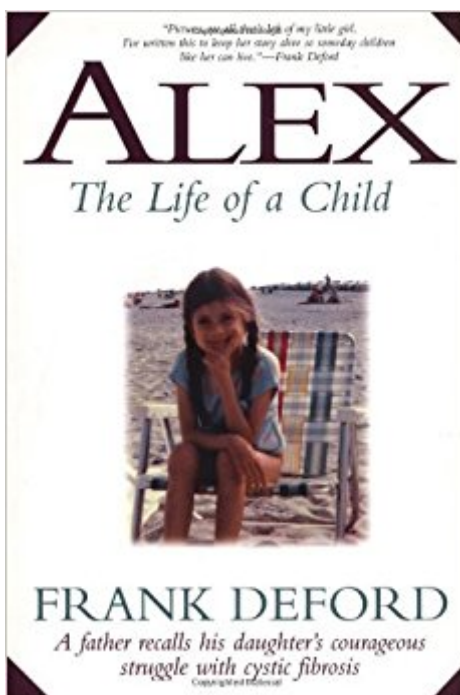


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# Alex: The Life Of A Child



## Synopsis

Alexandra Deford, a precious and precocious girl, was just eight years old when she died in 1980 following a battle against the debilitating effects of cystic fibrosis, the number-one genetic killer of children. Her poignant and uplifting story touched the hearts of millions when it was first published and then made into a memorable television movie. A new introduction contains information on the latest cystic fibrosis research, and a touching postscript reveals how the Deford family came to terms with the loss of Alex. Whenever he speaks, sportswriter Frank Deford knows people will bring articles for him to sign. But what makes him happiest is when someone attends a sports-oriented lecture and brings a copy of *Alex: The Life of a Child* for him to sign. "Invariably, and happily, there's usually someone at each appearance who either brings that book or wants to talk about their connection to cystic fibrosis." Deford says. "It's tremendously gratifying to me. Rarely does a week go by that I don't get a letter about that book. People leave things at her grave. They really do. I have people tell me that she changed their lives. It's terribly dramatic, but they literally say that. I heard from a woman who became a pediatric nurse after reading the book. Hearing from people like that means more to me than anything."

## Book Information

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## Customer Reviews

Frank Deford is a sportswriter and sportscaster whose work appears in *Newsweek* and *Sports Illustrated*. He is also a regular commentator on NPR and ESPN. He has published works of fiction, written movie screenplays and won an Emmy and a Cable Ace award. And he has served for over

10 years as the chairman emeritus of the Cystic Fibrosis Foundation. --This text refers to an out of print or unavailable edition of this title.

I first discovered this story in the December 1984 Reader's Digest in the featured book section. Even abbreviated, it was staggering. I saw the TV film later on, and still later, I found and bought the whole book. Since then, few January 19th's, the anniversary of her death, have passed that I have not thought of Alex and the family she left behind. I might do her memory more justice if I remembered her birthday instead, but her father did not write of her birth the way he did of her death. Frank Deford is an excellent and prolific writer of both fact and fiction and who makes personal to the reader every event he shares of Alex's life and death. Especially her death. Perhaps he didn't mean to make her death more poignant than her life, but it would be impossible to play it down. He paints nearly every hour of that last day of her life so vividly that I wondered if he was taking notes as it happened; he did, after all, keep a personal journal (no, I don't believe that he kept a notebook by the side of his dying baby's bed, only that he wrote it in such detail that it was as if he had done so.) These days, most people who die of lengthy, drawn-out illnesses die peacefully, only semi-conscious, doped up to the gills against unbearable pain. But though Alex might have been in pain, death did not take her peacefully. She didn't fight it, but neither did she go quietly. She was awake and aware to the very last second of her short life. As he said, she had spent so much of her little life dying that she wasn't about to miss the final act when it came. It was difficult enough to read when I wasn't yet a parent. It became even more meaningful after I became a parent. And then still more, when my daughter was diagnosed with a brain tumor. Alex's story made me aware of cystic fibrosis, to the point that I felt compelled, once I was gainfully employed, to begin contributing a few dimes a year to the CF Foundation. It's never been very much, but neither has the foundation ever returned an uncanceled check to me claiming it was too little to accept. Other parts of the story make strong impressions, such as her ability to act and mimic anything she saw on a TV or movie screen; she could have been an actress, or maybe a dancer, as she loved to twirl around with grace and energy, "imaginating" a world in which no one suffered pain or death or had to do therapy. The deep and serious discussions with people outside of her family circle regarding death, God and Heaven and her love of jokes and humor and silliness. Her obsession with beauty and jewelry, and the outrageous insensitivity with which she was treated several times by cold and heartless doctors. Fortunately, I can say that today, through my own experience with doctors and hospitals, the medical staff in the pediatric departments treat their young patients with great respect and compassion. We could wish that ALL types of childhood ailments were written about as beautifully.

There are other illnesses and disabilities that are just as deadly. He states at one point that "some diseases, even some fatal ones, don't put too many demands on the family of the patient." I felt like that wasn't quite a fair statement. If a loved one has a disease, particularly a potentially fatal disease to one's child, the demands of just living day to day with the knowledge that you will never be able to take for granted your child's good health is a pretty difficult burden to carry, not to mention the 'round-the-clock effort devoted to simply making the child comfortable. I do hope that I'm mistaken in his meaning of that statement. I can't imagine he would truly intend to dismiss other fatal illnesses children suffer as being easier to deal with. But then really, this story isn't really about sick children. It's not even about cystic fibrosis; it is about Alex, and there is only ONE Alex Deford. I know that there is, as he says, no value in losing your child. You don't gain anything meaningful from it. But because the rest of us have had the good fortune to stumble onto his story of Alex, many, many thousands of others have found meaning in their own lives as a result of Alex's life, however brief it was. The CF Foundation has also benefited. So, thank you Alex, for living, and thank you, Frank Deford, for sharing your daughter with the rest of us.

Alex Deford was born in 1971 and died just 8 years later in 1980. She had Cystic Fibrosis. Alex: The Life of a Child is the story of her life as told by her father. When I was 12 or 13 I bought a copy of this book at a yard sale. I read it multiple times. For some reason I really loved the story of Alex. It's been years since I last read it and it is still a great story. It is touching and told with such honesty and heartbreaking love. I highly recommend reading it.

This version of the book is abridged. Several key parts are left out, including Mr. Deford's discussion of how they came to adopt their daughter, Scarlett. This is a wonderful book, but the Kindle version is abbreviated. I recommend getting a version in print.

So I cried. And I mean cried! This book was so beautifully written. I read it in one day. I just couldn't put it down! I felt so connected and felt a part of their family and I felt like I was grieving and dealing with their struggles with them. What a beautiful story of such a beautiful little angel.

Very good book. This is the life of Alex, a little girl who dies of cystic fibrosis at age 8. It talks about the disease, what it does to the child, & the family. How it gradually takes over a person's life until there is nothing left. Alex was very brave & wise beyond her years. The author lets you into those final moments of her life, how she faced them & what it is like to watch your child die. A real tear

jerker - not for the faint of heart.

Alexandra Miller Deford was born on October 30, 1971. She died on January 19, 1980, sitting straight up and eyes wide open, with her parents, Carol and Frank at her side. Her life was taken by a genetic disorder, Cystic Fibrosis (CF), an incurable monster that ravaged her body and took everything from her except her amazing influence on others and the gut-wrenching story of her life. Alex: The Life of a Child was written by her father, and published in 1983. I have not read any other books or articles by Frank Deford; however, my guess is that this is the most poignant story he has ever told. As a frail baby, when Alex was diagnosed with CF, she was not expected to live more than 5 months, but she was a fighter who struggled to be as normal as possible, never using her disorder as an excuse for not participating. Many of her childhood friends were influenced by Alex and are practicing the field of healthcare. Over the years this book has been used in schools to educate children as young as 10 years old. Having never met her, other people inspired by this book or the movie, visit her grave site and have joined the plight seeking a cure for CF. According to my research, CF is primarily a disease that is much more prevalent with Caucasians and "over 90% of the affected infants now survive beyond one year." Studies show "the life expectancy of cystic fibrosis patients has been increasing over the past 40 years. Life expectancy of individuals with adequate pancreatic function can be more than 50 years." Alex lived, loved and set an example for the ages. She was a poster child for CF. She was an angel of a daughter. Her brother, Christopher was her idol. More than anything she wanted to live and be free of CF. She worried about the impact of her death upon her loved ones. She lives on in the hearts and minds of those who know her story. Alex would be 41 now, had she survived, yet she will forever be the brave little girl who lives in the pages of this unforgettable story told by her father in a manner that will squeeze your heartstrings and make your eyes moist and glisten with sadness, joy and awe. Celebrate and enjoy the life of an angel!

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