

"Photograph of my little girl.  
I've written this to keep her story alive so someday children  
like her can live." —Frank Deford

# ALEX

*The Life of a Child*



FRANK DEFORD

*A father recalls his daughter's courageous  
struggle with cystic fibrosis*

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## Alex: The Life of a Child Frank Deford

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."

## Alex: The Life of a Child Details

Date : Published July 30th 1997 by Thomas Nelson (first published 1983)

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Author : Frank Deford

Format : Paperback 142 pages

Genre : Nonfiction, Biography, Autobiography, Memoir, Death

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## From Reader Review Alex: The Life of a Child for online ebook

### **Heidi Hertzog says**

I read it as a young teen and it affected me so much and I have never forgotten Alex. As a young woman I volunteered at an auction for Cystic Fibrosis for a number of years. Why, because of this book. As a woman dealing with infertility, I remember a part of the book when Frank is in line at the grocery store buying root beer for his dying daughter and wondering to himself how everyone else's life is so normal, while he's buying root beer for his daughter who is at home dying. Made me relate in that while my world seems to be crumbling, others are dealing with their own private joys and grief. We can never know if the person in line at the grocery store is celebrating in their hearts over good news or merely holding it together until they can get in their cars or homes to fall apart. As a parent, I can't imagine watching my child suffer and die. If a book is rated on how it stays with you after you've read it, then this one ranks up there with 5 stars. It's stayed with me for almost 30 years. You can't say that about very many books.

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### **Sam says**

I'm actually surprised to see that so many people read this book as a pre-teen... at least I know that I'm not the only masochistic weirdo! haha!

Anyway, I remember stumbling across this book as it was delivered in the mailbox (for free) in one of homes that my father was having renovated and he brought it home for me to read. I was a voracious reader and would read anything that I could get my hands on...

but this book really stood out to me because it really touched my heart. I have it on my bookshelf and every time I see it, while I am searching for something to read, I am reminded of Alex and her story.

The story is tragic and sad but so well written... especially for a man who is not an author, but a father... and especially on a topic like this... that undoubtedly caused much pain and heartache.

I can honestly say that this book has really had some sort of effect on my life (I got very interested and involved with "65 roses"), so I definitely think it is a must-read for anyone.

You might cry though the whole book like I did... but it just might be worth it..

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### **Bruce McDonald says**

This is the only book I have ever read that made me cry, sobbing, out loud. It left an indelible impression on my life. There have been many advances in treatment since Alex died gasping in her father's arms, trying to the last to reassure and comfort him. CF still takes many lives too young, and there is still no cure.

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## **Marie says**

I cried on almost every page of this book...there is heartbreak on every page. I saw the TV-movie of Alex's story in the late 1980s as a kid and it really touched me. This year when a friend of a friend died of the same disease-cystic fibrosis-I immediately thought of Alex's story and knew it was time to read the book.

Alex was born in 1971 and died in 1980, a time when there wasn't many advances in treatment for the horrible disease. It's a heartbreakin story that I wish did not exist; however, her father writes about her with the utmost love and respect--in fact she had an amazing spirit and zest for life and he writes that he learned more about life and death from her than she probably learned from him. He writes frankly about the disease and the many struggles it put upon his little girl, family and himself. He is honest about his hatred for the evil disease, frustrations with doctors, prejudices, questions his faith at times and the difficulties of helping his wife and son grieve.

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## **Eva Leger says**

I don't know what to say about this book. I think everyone should read it. And at the same time no one should read it.

I cried so long and so hard last night that when I woke up this morning I couldn't see through my contacts. I had to throw them away- they couldn't even be cleaned. I felt like someone rubbed sandpaper on my eyeballs. I haven't sobbed as much as I did last night in the last decade and that is 100% true.

I've read dozens upon dozens upon dozens of true crime stories. Add to that dozens upon dozens upon dozens of victim memoirs from survivors of abuse, all sorts of abuse. But that's the thing- survivors wrote those stories. The true crime stories are often cold in a way- telling about the act of the crime itself and the murder(s) and very little about the victim(s). This was the complete opposite.

I feel like I knew Alex. I feel like I saw and can remember her mannerisms, her personality, her words, everything. I don't know, not only how her family got through this, but how her Dad wrote this book. It's so beautiful and so tragic all at the same time. I have tears in my eyes just thinking about what I read.

I'm glad it didn't take reading this book to know how lucky I am to have my daughter but it did drive it home. After I finished this book I crawled into bed with my daughter, who is roughly the same age as Alex was when they realized she was sick and not going to live, and just held her and thanked God.

The book shows you how a disease like cystic fibrosis literally tears a family apart and tried to kill everything within its victim. It also shows you how one little 8 year old girl wouldn't give in and let it win, no matter what. I thank God Alex was lucky (lucky- strange word to use in terms of her) enough to have the family that she did- she was loved like some people never, ever know.

I wish I knew how she got the strength that she had. At 8 years old. Here:

*...And so I carried Alex into her treatment room. By then she had prepared herself fairly well, but as soon as she saw that stark table where she was to lie and receive her shot and her incision, she stiffened and was the little girl again. 'No, not yet! Not yet!' she cried, and she clung to me as tight as she ever had.*

*I remember noticing that both nurses turned away from us at that moment, because, for all they might see, day after day in a hospital, there was such an awful intimacy to Alex's gesture that they could not bear to intrude on us. I only held Alex and tried to comfort her more.*

*And, in time, when she had composed herself, she said, 'All right. I'm ready now.' And so she was.*

*So I started to lay her down where they would cut her open. And in that moment, I could not hold back any longer; one tear fell from all those welling in my eyes. And Alex saw it, saw my face as I bent to put her down. Softer, but urgently, she cried out, 'Wait!' We all thought she was only delaying the operation again,*

*but instead, so gently, so dearly, she reached up, and with an angel's touch, swept the tear rom my face.*

*I will never know such sweetness again in all my life.*

*'Oh, my little Daddy, I'm so sorry,' is what she said. One nurse turned and bowed her head and began to sob. The other could not even stay in the room. She ran off to compose herself.*

I don't know if this is something most or all people feel but I feel pain inside when I read that. Actual pain to know a baby went through this. Went through that much pain.

I know I won't ever be able to read something like this again. And I also know I won't ever forget this book.

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### **Hilary says**

The only reason I wouldn't give this five stars is because I don't know if I ever want to read it again...it's too sad!

This is a true story about an 8-year-old who dies of cystic fibrosis. What makes the story so inspiring is how amazing little Alex was. She was brave and accepting as well as spunky and happy. It made me hope my daughter will be as unique as Alex was!

I also appreciated the writing. It's written by her father and he is frank and honest about the reality of how hard it is to live with a dying child. It made me wonder how I would cope. Made it very easy to read and made him very relateable.

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### **Alexandra Osterhoudt says**

I have never read a book like this one, from a parents point of view caring for a terminally ill child. While I thought I could only be crying through out this entire book, it was not like that at all. Yes the end of the book is very sad, have tissues handy but so much of the book was uplifting & inspiring .... how the author & his wife & child Alex lived 8 years of her short life. Having spent sleepless nights with a child with breathing difficulties I was able to identify with Frank & his wife. I read the first half of the book as I listened to my own son cough & try to get to sleep with a cold.....thinking about how each day of their lives must have been. For me this book helped me go on with the daily challenges that I face with each of my children .....no matter what happens we just need to love them and support them as best we can. I would recommend this book to anybody & everybody.

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### **Regina says**

It's hard to say how many times I read this book when I was growing up, or how many times I watched the subsequent TV movie. What I do know is that there are moments that are burned into my memory, as if I had lived through them myself. Upon re-reading this now as an adult, it's easy to see why Alex's story made such an impression. It's tragic and heartbreak, but it's also told skillfully by her loving - and talented - father Frank Deford. In my eyes, "Alex: The Life of a Child" is a modern classic.

### **Joye Austin says**

This is one of the most influential, meaningful books I read as a young girl. It was the first time a book ever made me cry, and I've seldom been touched so deeply by a story since. I read it many times, and it never lost its impact. I still think of Alex to this day, as an adult; especially now that I have my own children. The memory of her father's account of her life is very vivid, years later.

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### **Brian says**

I read this at ten years old. The book made me cry.

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### **Sarah says**

Everyone knows cystic fibrosis is a horrible disease. However, reading the account of a father watching his child die - I had not realized just how truly brutal it could be to all involved, how this disease could take over the lives of all it touched.

This is an unvarnished, unflattering account of a little girl who knew at a very young age that she was going to die badly, and how she came to terms with it. I thought at first the writing style was too simplistic, until I saw how much more powerful it was.

The one quote that really stuck with me was this, near the end: "I really only know this one thing for sure: there are no lessons to learn from having your child die. There is no value in it whatsoever."

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### **Dan says**

Frank DeFord wrote this book shortly after his daughter, Alex, died in 1980 from cystic fibrosis at the age of eight.

This is as one might expect, a highly emotional read. I love Frank DeFord's writing and this was his most popular book. I had been putting it off because it is a very sad topic but I gathered up the fortitude to read the book.

After the first few introductory chapters, the writing wanders around and it is really when Alex is old enough to write and ask grown up questions about her condition that the book came together. DeFord also wrote about how hard on a marriage the universal guilt is and that is in addition to the constant full time care Alex and other CF patients require.

Moving toward the end of the book it was impossible to read the last chapters with dry eyes. When Alex knows she will die and asks so many questions about God and angels and expresses some healthy doubt about both, the adults reassure her. There is a section where the Children's Hospital had patients write out

what they would be doing when they were adults.

“What will I be when I’m 23?  
I’ll be a scientist and I’ll be a enveter and go to the moon.  
What will I be when I’m 43?  
I’ll see other children growing up and seeing new things.  
What will I do when I’m 62?  
I’ll chat on the phone a long, long time like my Nana does.  
If I’m alive at 95 ...  
They’ll have a new inventians. I’ll sit in my old rocking chair.”

The last chapter, when Alex finally succumbs to her disease at home with Mom and Dad, is as an emotional chapter as I have ever read. DeFord writes

“I’m sorry, but this is how a child dies. I can see those eyes, this moment, still. I see them constantly. But I could never describe them properly for what they meant, what they told ...”

Frank DeFord passed away in 2017.

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### **Joanne G. says**

I read this book when it first came out, and it has stayed with me for 30+ years. When my infant daughter was ill, a doctor wondered if she wasn't suffering from CF. My heart plummeted, and I must have had a stricken look on my face, because the doctor quickly assured me that CF wasn't an immediate death sentence. I remembered all the hardships of Alex and her family, and her heartbreaking death at the age of eight. The doctor informed me that CF patients could expect to live until 20. Thankfully, today, the survival rate is almost 30 years.

Little Alex's story has probably done more to raise awareness of cystic fibrosis than any other single person. I'm so sorry she wasn't able to benefit from the research and new drugs.

Edit of 03/05/2016: I'm happy to say that the outlook for those suffering with CF has continued to improve: "Overall, the improvement in survival witnessed among those with CF in absolute terms, in those countries studied, is considerable and supports the assertion that a median survival in excess of 50 years for those born in 2000 should be expected." - <http://www.ncbi.nlm.nih.gov/pmc/article/2016/03/05/27>

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### **Rebecca Causey says**

This was an AMAZING book. I normally don't read books like these but I was given this book, along with some others, to read. I'm so glad I did because it was truly an amazing read and I loved getting to know Alex and her family. She was such a bright girl, despite her disease, and so strong from it as well. I highly recommend this book.

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### **Sylvester says**

I wish Frank Deford could know that I will show kindness to other people in memory of Alex. I wish I could thank him for telling us about her, because without this book we would not have known how wonderful she was. One person can change how we live. Alex was one of those people.

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