

## Resources for Patients and Families

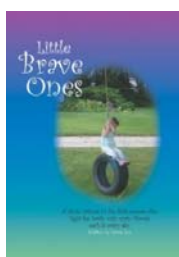
### *Books For Children*

#### **Who I Am! By Genentech**

This hardback children's book is beautifully illustrated by Pixar artists and takes readers (young and old alike) into Patti's world for a school report about "who she is." Lighthearted and playful, this book also touches on the important CF issues of adherence, nutrition, and infection control. Free from Genentech, contact your CF clinic to get a copy.



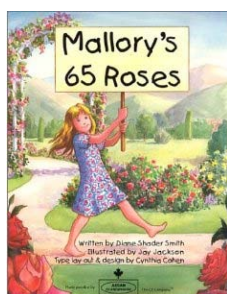
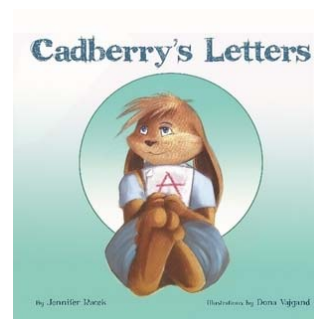
#### **Little Brave Ones: For Children Who Battle Cystic Fibrosis by Carrie Lux**



Written by a CF mother of a 4-year old, the book uses pictures and a simple story to share a day in the life of a preschooler with CF.

#### **Cadberry's Letters by Jennifer Racek**

Cadberry's mom is very forgetful. When they visit his doctor together, she talks about C & F but never remembers the other letters. When Cadberry draws a set of letters to help his mother remember them all, he discovers what C & F really mean and how those two tiny letters affect so much of his life. Developed for pre-school-age children, the book uses simple, easy-to-follow language to explain cystic fibrosis and the daily care that goes along with it in terms young children can understand.



#### **Mallory's 65 Roses by Diane Shader Smith**

The engaging story of Mallory, a creative and energetic little girl with CF. She explains her condition and its ramifications in her own words, painting a picture accessible to children and poignant to adults.

#### **Charlie and Me by Kathryn Archambault**

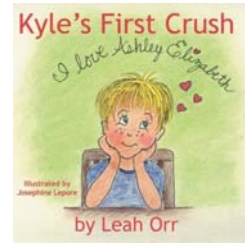
This heartwarming true story is about a boy with CF and his best friend Kathryn. They grow up together, sharing challenges and finding the courage Charlie needs to battle his disease every day. Children and adults will find comfort and strength in Charlie's story and the realization that with a friend by your side, you can get through anything.



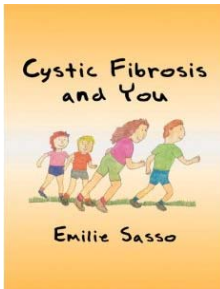
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### **Kyle's First Crush by Leah Orr**

Kyle falls in love for the first time in Miss Irene's Pre-K Class. Ashley is a very special girl who melts his heart. With some help from his mom, he finally tells Ashley Elizabeth how he feels about her.



### **Cystic Fibrosis and You by Emilie Sasso**



This book is all about having a positive attitude in life and accomplishing your dreams. My hope in writing this book is to give encouragement to children and teens with cystic fibrosis. My sisters Bonnie and Kate accomplished everything in this book and more with CF. Never let cystic fibrosis hold you back from living life to the fullest.

### *Videos about CF for Children*

Note: Videos are posted on [www.TipsForCFParents.com](http://www.TipsForCFParents.com) under "Teaching Children About CF".

### **Getting Nosey About CF with Oli and Nush**

A short film made by the Cystic Fibrosis Trust ([www.cftrust.uk](http://www.cftrust.uk)) by Absolutely Cuckoo to help children with CF understand their condition and to explain to other children what CF is.

Link: <http://www.youtube.com/watch?v=WuI72eMrIQI>



What is Cystic Fibrosis? Animation for CFF San Diego



### **What Is Cystic Fibrosis?**

Animated video provides facts about CF. Created for the San Diego Chapter of the Cystic Fibrosis Foundation's ([www.CFF.org](http://www.CFF.org)) CureFinder's in-school program.

Link: <http://youtu.be/FMAOEOmLoUE>

### **Welcome to Joshland**

Josh Mogren has created several videos for children with CF with his puppet named "Moganko" including: PFT Tests, Hospital Visits, and lots more. Josh is incredibly inspiring, positive, fun and has cystic fibrosis.

Visit [www.WelcomeToJoshland.com](http://www.WelcomeToJoshland.com) for Josh's videos and blog.

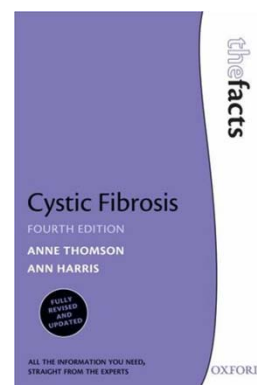


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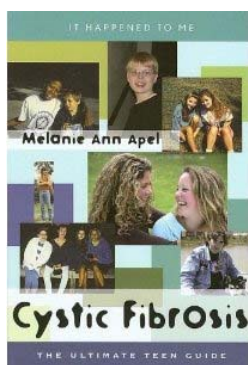
### Books for Teens

#### **Cystic Fibrosis (Facts) by Ann Harris and Ann Harris**

Cystic Fibrosis: The Facts provides a much needed simple and understandable source book about this disease. The book explains clearly what is happening to the body in CF, what causes it and what treatment options are available for the different aspects of the disease. There are more detailed chapters for those wanting to find out about the genetics of the disease and specific aspects such as how it affects life choices and employment. It looks to the future in terms of potential new therapies for CF and provides useful information on organizations that can provide help and further information across those areas of the world where the disease is prevalent.



#### **Cystic Fibrosis: The Ultimate Teen Guide by Melanie Ann Apel**



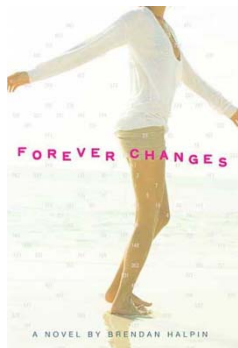
A solid introduction to the disease - the facts, the challenges, the complications, and the outlook for the future. The day-to-day dealings of life as a patient are described, including: who gets the disease and why; an explanation of the procedures involved in diagnosing CF; the arduous daily therapies; and the challenges of dealing with CF-related diabetes. These teens' stories reflect how they live their lives to the fullest, how they are not bitter about their situations, and how they look forward to new medications, more-effective therapies, and a cure. Also included are stories told by patients now in their 30s and 40s, who are still alive and coping well with the disease, demonstrating that progress is being made and that they can hope to live beyond their teen years.

#### **Sick Girl Speaks!: Lessons and Ponderings Along the Road to Acceptance by Tiffany Christensen**

*Sick Girl Speaks!* contains a lifetime of patient experiences, lessons and emotional reflections. Tiffany has spent decades in the medical system making mistakes and overcoming obstacles. The time has come, after her second transplant, to tell patients and families what she knows. Tiffany advocates a spirit of acceptance entwined with logical strategies to make life better; no matter the physical outcome. The book combines anecdotal teachings with honest journal entries. The road to acceptance is a winding one and the reader will see contradictions even within a few short pages.



#### **Forever Changes by Brendan Halpin**



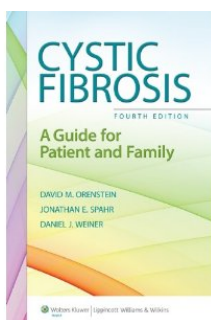
Brianna, a high school senior and verifiable math wizard, is sure to be accepted at MIT. She also has CF. The death of Molly, a friend who also had CF, haunts Brianna and she fears that she will be next. With her body slowly failing her, she sometimes doesn't see the point of applying to college or thinking about her future. Comfort comes from two unlikely sources. Adam, a dorky new friend from math class introduces her to Love, a 1960s band whose lyrics speak to her. Mr. Eccles, her calculus teacher, also facing his own mortality, teaches her about infinitesimals. These quantities are important in calculus: "Something which seems to be nearly nothing turns out to be crucial to everything." Brianna finds strength in this idea when confronting her own mortality and the value of her life.

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### *Books for Adults*

#### **Parenting Children With Health Issues: Essential Tools, Tips, and Tactics for Raising Kids with Chronic Illness, Medical Conditions, and Special Healthcare Needs by Foster W. Cline and Lisa Greene**

Special parenting skills are needed to raise kids with special health needs. Inside this book, you will find the essential parenting skills to help your child comply with medical requirements, cope well with health challenges, and live a hope-filled life. Get practical and compassionate answers as you learn effective ways to communicate about health issues with children of all ages. A condensed version is also available in English and Spanish. A three hour DVD version is also available. [www.PCWHI.com](http://www.PCWHI.com)

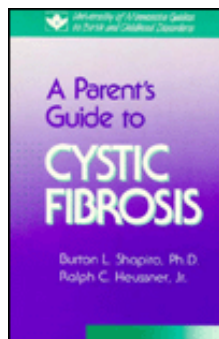


#### **Cystic Fibrosis: A Guide for Patient and Family by Orenstein, Spahr, and Weiner**

Newly updated in 2011, this one-of-a-kind guide offers easy-to-understand explanations, advice, and management options for patients or parents of patients with cystic fibrosis. The book explains the disease process, outlines the fundamentals of diagnosing and screening, and addresses the challenges of treatment for those living with CF. As one reviewer said, this book “is the only complete answer book for everyone living with the disease. It is an indispensable resource for families of children with CF, adolescent and adult patients, and physicians, nurses, respiratory therapists, and social workers involved in the care of CF patients.” Available for free for CF patients at CF clinics.

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### Parent's Guide to Cystic Fibrosis by Burton Shapiro

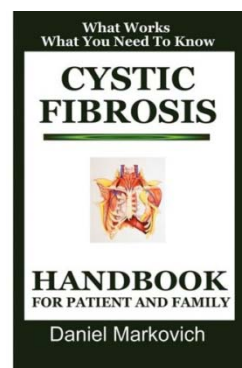


Explains in detail the genetic causes and biological effects of cystic fibrosis as well as its social and psychological ramifications. The authors describe how the body's various systems—respiratory, digestive, reproductive, and musculoskeletal—respond to the disease, and they discuss the rationale behind the strategies employed to control it. Recent advances in treatment are summarized and a synopsis of some of the more promising research on the horizon is provided. Stressing a personal, informative approach, the authors have augmented the text with case histories and comments from parents and patients. An entire chapter is devoted to family life, and selections from a “family diary” round out the chapters.

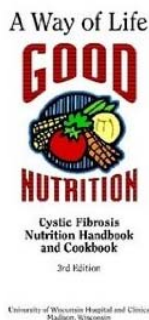
[http://www.upress.umn.edu/Books/S/shapiro\\_parents.html](http://www.upress.umn.edu/Books/S/shapiro_parents.html)

### Cystic Fibrosis: Handbook for Patient and Family edited by Daniel Markovich

This guide offers clear explanations, real-world advice, and practical and reassuring information on day-to-day concerns—school, travel, exercise, nutrition, medication—as well as on physiological effects, long-term issues, and prospects for a cure. The book offers straightforward answers to the questions most frequently asked by patients and families - what causes CF; how it affects body systems; what pharmacological, surgical, and physical therapies are most effective; what roles exercise, diet, and nutrition play; what complications can occur and how they can be managed; when and why a lung transplant should be considered; what psychological effect the disease has on the patient's family; and how the special needs and concerns of adult CF patients can be addressed.



### A Way of Life: Cystic Fibrosis Nutrition Handbook and Cookbook by Lisa Davis, Erin Tarter, Toni Lawand Mary Marcus

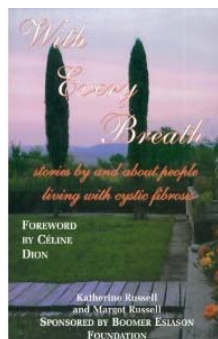
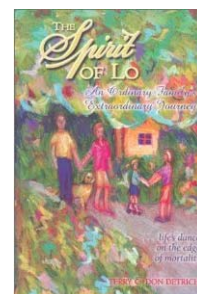


This handbook/cookbook is designed to help explain how CF affects the human body and the role diet plays in managing the disease. The first half of the book describe the challenge of eating enough of the right types of food to support growth and development, fight infections and lead a productive life and guidelines for creating a healthy diet that meets the needs of people with CF and tips for applying those guidelines to day-to-day living. The last half of the book contains more than 130 favorite recipes provided by CF patients & families and by University of Wisconsin Hospital and Clinics Clinical Nutrition Department.

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### **The Spirit of Lo: An Ordinary Family's Extraordinary Journey** by Terry & Don Detrich

An ordinary family is faced with an extraordinary challenge, a child with cystic fibrosis. This is their story, rich and moving, as they laugh and cry and learn and grow. Their love, faith, and commitment to each other carry them through battles with depression, anger, despair, and the ravages of the disease as they join a race with death for a cure. What emerges is *The Spirit of Lo*, which enables the family and their community to face each new day of life's dance on the edge of mortality.



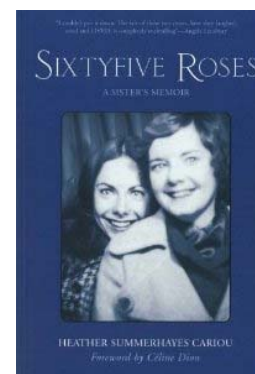
### **With Every Breath: Stories By and About People Living with Cystic Fibrosis** by Katherine Russell and Margot Russell

Created to motivate, inspire, and generate positivity for those living with cystic fibrosis, this book is something you can open time and time again. Designed for all ages, this collection of diverse stories offers unique perspectives from patients, a CF doctor and nurse, and family members of those living with the illness. Patients aren't the only ones who will want to read this book, as family members, friends, and doctors can all find inspiration when they open it. The stories range from overcoming challenges, understanding the disease, lung transplants, diagnosis stories, and more. The book is

filled with fun artwork, uplifting quotes, and photography. Forward by Celine Dion.

### **Sixty-five Roses: A Sister's Memoir** by Heather Summerhayes Cariou

An honest, chilling tale of a family dealing with chronic illness, this memoir's subject is Cariou's sister, Pam, who at the age of four was diagnosed with C F. Unable to pronounce her condition, young Pam dubs it instead "Sixty-five Roses." What follows is no heartwarming tearjerker; early on, Cariou cagily warns that "the world of chronic-terminal illness is, in many ways, akin to the world of war." Written to fulfill a deathbed promise Cariou made to write "our" story, and a promise to her mother to tell the truth, the result frequently is not pretty. Initially given no more than six years to live, Pam was among the first wave of Cystics to reach adulthood (she died at 25), but her life is a daily struggle, crammed with treatments, hospitalizations, false starts and faint hope, setbacks and unfulfilled dreams. Cariou communicates well the complicated feelings that long-term illness can breed in families.



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### *Organizations & Websites*



The mission of the Cystic Fibrosis Foundation is to assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease. The Foundation is the leading organization in the United States devoted to cystic fibrosis. It funds and accredits more than 115 CF care centers, 95 adult care programs and 50 affiliate programs, and more than 75 chapters and branch offices nationwide.



CysticFibrosis.com is a social health community, founded in 1996 at the dawn of the Internet and the rise of the e-patient – the electronic or empowered patient. CysticFibrosis.com is a source of information, hope, and encouragement for patients and families affected by CF. The site educates patients, families, and the community in comprehensive and innovative ways: forums, chats, videos, newsletters, polls and blogs. The Know CF section of the site offered timely and crucial information on the H1N1 virus and CF last fall, followed by a unique video series on parenting children with health issues.



The Reach for the Stars Foundation is dedicated to providing individuals afflicted with Cystic Fibrosis and their families with the resources, knowledge and support necessary to manage their unrelenting battle with this insidious disease. Cystic Fibrosis is not only physically debilitating, but carries a heavy financial and psychological burden for families.

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KidsHealth creates online, print and video media about a wide range of health and family issues and is the largest resource of online children's health information written for three distinct audiences: parents, kids and teens. Through engaging, easy-to understand media, KidsHealth provides knowledge, advice, comfort, and perspective to families on a wide array of medical, behavioral and developmental topics.



CysticLife's mission is to immediately transform the lives of those afflicted by Cystic Fibrosis and make Cystic Fibrosis personal for those not personally affected. CysticLife launched a social network for the CF community in 2010.



An online community for people of all ages living with cystic fibrosis. A place for motivation, inspiration and connection to the CF community. Offering free registration for the latest cystic fibrosis news, exclusive podcasts and a treatment tracker customized to your treatment schedule.



<http://www.cfliving.com>

CF Living is an online resource designed to offer information and support for those living with or caring for someone with cystic fibrosis. Patients/family members receive personalized emails with valuable information about CF, as well as:

- Tips for administering treatment
- Information about the progression of CF
- Links to additional resources they can turn to every day



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<http://www.TipsForCFParents.com>

Tips for CF Parents provides practical tips and resources for parents of children with CF. Lisa C. Greene is the mom of two kids with CF, a parenting coach and co-author with Foster Cline, MD of the award-winning book "Parenting Children with Health Issues".

Resources include articles, audio and video clips for food and school issues, hospital stays, stress management, transition, ages and stages, teaching children about CF, tips for summer camp, sibling issues, and funny stories for CF parents.



<http://www.PCWHI.com>

Parenting Children with Health Issues offers free audio, video, articles and other resources to help parents discover how to raise happy, healthier kids. Based on the popular Love and Logic ® parenting program created by Jim Fay and Foster Cline, MD (www.loveandlogic.com).



<http://cf.starlight.org/>

*Fitting CF Into Your Life Every Day* is an interactive, animated program was written with help from a panel of teens with cystic fibrosis (CF) to help other teens and pre-teens ages 10 to 15 as they begin to take on more responsibility for managing their disease and their treatments while still enjoying all the things they love to do.

The program was designed to help teens better understand core CF management principles, and features animated depictions of the lungs to help young people understand the importance of lung clearance techniques, medications, enzymes and diet. The website also offers an interactive

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question and answer section, where teens can find advice and tips from older teens with CF about challenges they may face. The website also links to Starbright World, an online social network where teens (ages 13 to 20) who have serious medical conditions, and siblings of seriously ill teens.



<http://bloomingrosefoundation.org/>

*The Blooming Rose Foundation's* mission is to provide social services, positive contacts and hope to families immediately after diagnosis with a basket of resources and contacts with other parents.