

Child Life in the Cystic Fibrosis Center



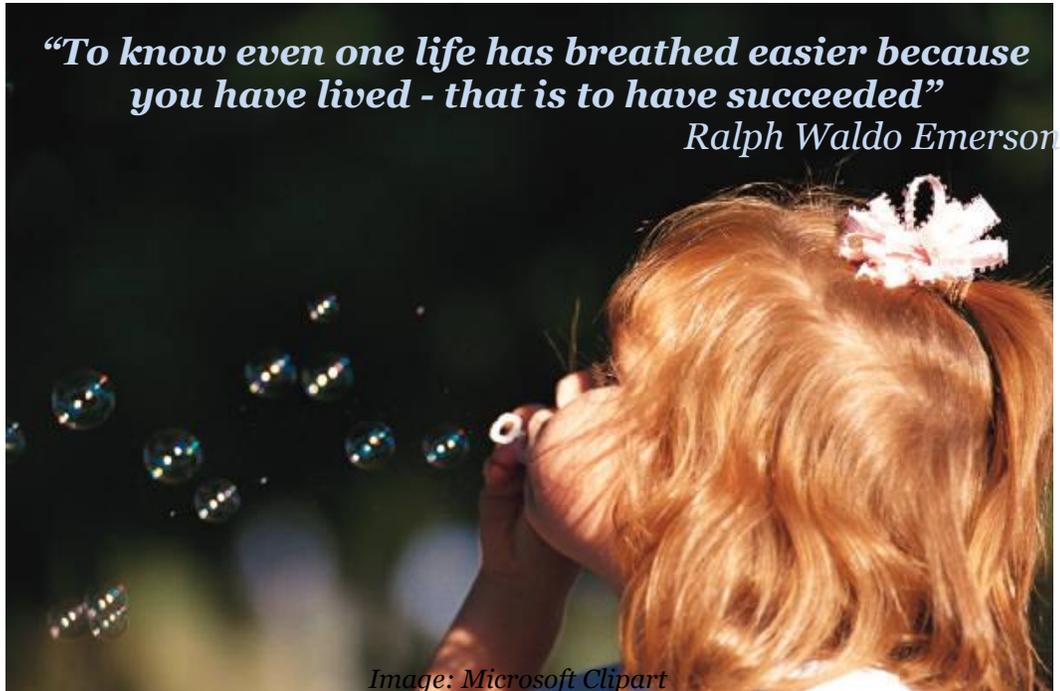
<http://www.cfparent.com/wp-content/uploads/2010/08/Juliamask.jpg>

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Mission

The mission of the Child Life Program at the Cystic Fibrosis Center is to advocate for and assist in meeting the psychosocial needs of patients and their families. By utilizing play as the primary method for providing developmentally-appropriate disease education and preparation, coping skills training, and opportunities for therapeutic expression, we aim to those affected by a CF diagnosis fulfill his or her maximum potential.

Vision

The Child Life Program at the Cystic Fibrosis Center will be a leader in the CF community by paving the path for integrating innovative child life techniques to improve patient outcomes through understanding, empowerment, and positive coping.

Values

The Child Life Program at the Cystic Fibrosis Foundation values the unique individuality of each patient and family, the importance of education in advancement of care, and the advancement of best practices through clinical research and professional development.

Adapted from:

<http://www.chicagochildlife.com/#ixzz1ACHX4Kp5>

http://www.connecticutchildrens.org/documents/depts/ccfc/CF_Center_Mission_Statement.pdf

The Role of the Child Life Specialist

The Child Life Specialist is a member of the psychosocial team that focuses on the social and emotional impact of illness and hospitalization on children. Their goal is to minimize the stress associated with medical experiences and foster optimum development. Child Life Specialists utilize play to promote effective coping through preparation, education, and self-expression activities. Because Child Life Specialists possess a strong background in child development and family systems, they understand the importance of the family in supporting the child. They encourage family-centered care by providing information, support and guidance to parents, siblings, and other family members. Child Life Specialists also use this knowledge of child development to educate healthcare professionals and administrators about the needs of children dealing with the stress of illness, medical procedures, and hospitalization.

Responsibilities¹

- Increase familiarity with clinic surroundings and to prepare patients and families for medical experiences
- Provides medical procedure preparation, support, and accompaniment whenever necessary to support the patient and/or caregivers
- Provide age-appropriate play, creative arts and other activities, encouraging mastery and understanding of medical experiences, building coping skills and allowing for expression of feelings
- Plans and facilitates activities and interventions in group and individual settings to help patients and families cope with medical situations and meet their developmental, emotional and cultural needs
- Develop supportive collaborative relationships with patients and families to assist them in achieving health care goals
- Provide opportunities for building independent behavior, retaining self-esteem and promoting transition to self-care
- Provide for continuation of normal daily activities so as not to interfere with appropriate growth and development
- Facilitate communication between medical personnel, the patient, and the family and advocate for child's developmental needs.
- Models developmentally appropriate interactions for patients, caregivers and staff.
- Records observations of child and family in the medical record so as to communicate effects of intervention to other members of health care team.
- Maintains a safe, therapeutic milieu in all patient areas and sustains appropriate professional boundaries with patients, caregivers and staff
- Coordination of special events, wish referrals, and other clinic programs
- Schedules, supervises and coordinates the activities of Child Life Program volunteers
- Participates in regular evaluations of Child Life programming so as to measure the effectiveness of the program
- Implements quality improvement strategies that include multidisciplinary meetings, review of program goals and documentation of quality improvement measures.
- Plans an annual budget for program materials and submits appropriate grant applications and reports to maintain funding for program
- Maintains knowledge of current professional trends, practices and techniques through participation in professional organizations, attendance at conferences, seminars and other continuing education programs

¹ Sources listed in Reference section of document

Typical Daily Schedule of Child Life Specialist

- 8:00 AM** Arrive at work and check emails/messages
- 8:30 AM** Review notes for day's clinic schedule and organize materials/supplies for appropriate patient education and interventions
- 9:00 AM** Provide appropriate educational interventions, expressive therapy activities, and procedural support/distraction as necessary with clinic patients and families
- 12:00 PM** Lunch
- 1:00 PM** Resume providing appropriate educational interventions, expressive therapy activities, and procedural support/distraction as necessary with clinic patients and families
- 3:00 PM** Return to office for charting of day's patient interventions and to check emails/messages
- 4:00 PM** Attend committee meeting
- 5:00 PM** Dinner
- 6:30 PM** Attend Parent Advisory Board meeting
- 8:00 PM** Close up Child Life Center and end workday



Image: <http://i.ytimg.com/vi/k3SokXPajxo/o.jpg>

Providing Family-Centered Care

Individuals, especially children, are not islands. They are valuable and integral parts of many social systems, but the most important to a child is the family. When an individual has CF, the whole family is impacted by the disease in a variety of ways, including:

- Financial burden
- Time spent providing care to the child
- Impact on parent's employment
- Missed school days for the child
- Separation of the family due to hospitalizations
- Strained parent-child, parent-to-parent, and sibling relationships
- Difficulty in maintaining social relationships due to burden of care
- The use of or need for prescription medication
- The use of or need for more medical care, mental health services, or education services than other children of the same age
- The use of or need for treatment or counseling for an emotional, developmental, or behavioral problem
- Limitation in the child's ability to do the things most children of the same age do

What is Family-Centered Care?

Family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting.

<http://www.ipfcc.org>

The cornerstone of family-centered care is active participation between families and professionals. Family-centered care recognizes that families are the ultimate decision makers for their children. In the early stages of development, the parent the decision-maker with children being given information and opportunities to gradually take on more and more of this decision-making themselves as they mature. When care is family-centered, services not only meet the physical, emotional, developmental, and social needs of ill and healthy children within the family but also support the family's relationship with the child's health care providers and recognize the family's customs and values

What are the core concepts of patient- and family-centered care?

- **Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration.** Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Suggestions for Family-Centered Care within the Clinic

Clinic Environment

- Photographs and credentials of all clinic staff displayed in prominent location
- Bulletin board to communicate important news and events
- Publish a clinic newsletter with sections written by each area of clinic (medical, nursing, respiratory, dietetics, child life, social work)
- Creating a website for clinic with patient education materials, newsletter archives, and password protected access to medical records, moderated support group discussions, and other tools for patients and families
- Educating and supporting patients through rotating series of posters in exam rooms
- Create a family resource center with a library check-out system for books, videos, and other materials

Pediatric Patient Programs/Services

- Speak in developmentally-appropriate language
- Allow the patient age-appropriate choices whenever possible in regards to medical treatment & care
- Develop of a patient notebook to record symptoms, medications, treatment schedule, and questions or comments
- Involve patients in the transition to self-care and responsibility by implementing a set of developmental tasks and supporting the patient in achieving these milestones
- Provide clinic notes at the end of each clinic visit
- Coordinate with hospital CLS to set up pre-hospital tour prior to first tune-up admission
- Utilize developmentally appropriate education about illness, treatments, and associated health issues using tools such as dolls, medical equipment, books, and photographs
- Provide preparation and support before, during and after medical procedures and other stressful times; assistance with coping techniques (toys, books, guided imagery and relaxation techniques)
- Create therapeutic play opportunities (medical play) to understand the child's perspective of his/her diagnosis or hospital stay
- Offer activities to give the child acceptable outlets for fear, anger and anxiety which might result from restrictive activity in an unfamiliar environment
- Institute an individualized program of activities to assist the child in maintaining equilibrium in the face of illness to prevent protected behavioral regression
- Implement a school entry/re-entry program with visits to a child's school to explain illness, injury, treatment and recovery to classmates, easing a child's transition from the hospital to the classroom.
- Celebrate special occasions and milestones related to CF self-care developmental tasks and treatment plan goals (Green Zone BMI, Removal of G-Tube, Able to Swallow Enzymes on Own)
- Solicit input from patients on clinic performance (services, staff, quality of care, etc.)
- Include patients on clinic committees
- Develop a system of open communication that covers clinic, home, school, hospital, and community
- Having an annual "family meeting" appointment where all members of the family have a chance to speak to the healthcare team
- Including an "about our family" form that is updated annually in medical chart to learn more about patient and family
- Have a patient story section in the clinic newsletter

Sibling Programs/Services

- Speak in developmentally-appropriate language
- Utilize developmentally appropriate education about illness, treatments, and associated health issues using tools such as dolls, medical equipment, books, and photographs
- Create therapeutic play opportunities (medical play) to understand the child's perspective of his/her diagnosis or hospital stay
- Offer activities to give the child acceptable outlets for fear, anger and anxiety which might result from restrictive activity in an unfamiliar environment
- Institute an individualized program of activities to assist the child in maintaining equilibrium in the face of illness to prevent protected behavioral regression
- Hold a "Teddy Bear CF Clinic" visit to help siblings understand what their brother or sister does at clinic and how the medical team is helping them
- Sibling Time playroom staffed with trained volunteers to offer parents a place to have siblings cared for during clinic visit but also a place for siblings to connect with one another and to engage in various medical and expressive activities
- Involve siblings in "family meetings" and other aspects of care as developmentally-appropriate
- Implement a sibling support group co-facilitated by older siblings and CLS
- Offer sibling social activities
- Enable sibling participation in activities such as "Fun with Food" cooking lessons and other volunteer-run support programs
- Solicit input from siblings on clinic performance (services, staff, quality of care, etc.)
- Include siblings on clinic committees
- Have a sibling section in the clinic newsletter

Adult/Caregivers Programs/Services

- Makes the parent feel like a partner in the child's care
- Explaining medical jargon in clear and easy-to-understand language
- Provide parents with information on the developmental tasks of self-care and support them in helping their child achieve the tasks in the path to transition
- Offering quarterly "Intro to CF" courses for parents of newly diagnosed patients – led by both healthcare professionals, adult patients, and experienced CF parents
- Recognize anxiety of parents and help them encourage recreational outlets for the child
- Provide continuing parent/caregiver education on childhood growth and development and the effects of illness, injury and hospitalization.
- Offer coping skills training workshops tailored towards common struggles parents face (struggles with weight gain, treatment compliance, time management and fatigue, etc.)
- Provides the specific information that the parent needs
- Offering adult/caregiver networking and retreats
- Implement a parent support group co-facilitated by parents with special topics/speakers as decided upon by parents involved
- Offer sibling social activities
- Enable sibling participation in activities such as "Fun with Food" cooking lessons and other volunteer-run support programs
- Solicit input from siblings on clinic performance (services, staff, quality of care, etc.)
- Include siblings on clinic committees
- Have a patient story section in the clinic newsletter

Adapted from:

http://beta.hrservicesinc.com/appone/branding/wvuh/MainInfoReq.asp?R_ID=459201&B_ID=20&fid=1&Ad=&CountryID=3

<https://www.cookchildrens.org/SpecialtyServices/Pulmonology/Services/Pages/cysticfibrosis.aspx>

<http://www.arthritis.org/ja-family-centered-care.php>

http://www.cfnz.org.nz/files/Adult_Booklet.pdf

<http://www.mcq.edu/centers/cpfcc/index.html>

Patient's Bill of Rights for Pediatric Patients

You have the right to:

Respect and Dignity

- We want to get to know you.
- We will tell you who we are, and we will call you by your name.
- We will take time to listen to you.
- We will honor your privacy.
- We will honor you/your family's beliefs and practices.
- We will not talk about you in your room or outside your door unless you know what is happening.

Information You Can Understand

- We will explain things to you in ways you can understand.
- We will tell you what we are doing to you and why we are doing it.
- You can ask questions if you don't understand what is happening to you or why.
- We will provide someone who speaks your language to help explain things to you or your parents.
- Information about you and your family will not be given out without you or your parent's permission.

Quality Collaborative Health Care

- You will be taken care of by doctors, nurses and other people who know about children and teenagers.
- You can know all the people who are on your healthcare team and ask for help or guidance from any them.
- Your ideas and feelings about how you want to be cared for are important.
- You can help decide how you want to be taken care of (choose where you want to have a shot or which ear will be looked at first).
- You and your family can meet with your health care team to plan what is best for you.

Care that Supports You and Your Family

- All families are different. We want to learn about what's important to you and your family.
- You can ask for something to make pain feel better.
- You can have a parent or adult stay with you during exams to help you feel safe and comfortable.

Emotional Support

- When you are in the clinic, you might feel scared, mad, lonely or sad. You can let people know how you feel.
- It is OK to cry or complain or laugh.
- We can help you communicate with other children and families who have had experiences like yours
- You can talk or play with people who know how to help when you have questions or problems.
- We will consider all your interests and needs, not just those related to your disease.

Adapted from:

http://www.centracare.com/hospitals/sch/services/pcw/family_friendly.html

<http://www.uwhealth.org/childrens-hospital-guide/bill-of-rights-for-children-and-teens/12208>

Bill of Rights for Parents

You have the right to:

Respect and Dignity

- We want to get to know you.
- We will tell you who we are, and we will call you by your name.
- We will take time to listen to you.
- We will honor you/your family's beliefs and practices.
- You can trust that your child will receive care and treatment in a way that respects him or her as a person with dignity.
- We will not share with anyone the files about your child's care.

Information You Can Understand

- You will receive information on diagnoses, treatments (procedures and medications, including any risks), expected outcomes (prognosis), and any training or instructions you need to learn to care for your child at home in language and words that you understand.
- You can ask questions if you don't understand what is happening to you or why.
- We will provide someone who speaks your language to help explain things to you or your child.
- You will be given information on what to do if you believe that you and/or your child have been treated unfairly or if you have a complaint.
- You can freely voice complaints and recommend changes without fear of a change in the quality of care your child is receiving.
- You may ask to see another doctor, get a second opinion, or change doctors or clinics.
- You can refuse to take part in the training of healthcare workers, research or in experimental programs.

Quality Collaborative Health Care

- You will be recognized as an expert on your child and your observations and concerns will be respected and listened to.
- Your ideas and feelings about how you want your child to be cared for are important.
- You and your family can meet with your health care team to plan what is best for your child and your family.
- You can take part in all decisions about your child's care and treatment.
- We will give you the names, professions and experience of the clinic team that cares for and treats your child.
- Your child will be taken care of by doctors, nurses and other people who know about children and teenagers.

Care that Supports You and Your Family

- All families are different. We want to learn about what's important to your family.
- You can ask for information about pain and pain relief measures.
- You can stay with your child during exams to help them feel safe and comfortable.

Emotional Support

- Dealing with CF can bring up a lot of different emotions. You have the right to feel scared, mad, lonely or sad and to let people know how you feel.
- It is OK to cry or complain or laugh.
- We can help you communicate with other parents and families who have had experiences like yours.
- You can talk with people who know how to help when you have questions or problems.
- We will consider all your interests and needs, not just those related to your child's disease.

Adapted from:

http://www.centracare.com/hospitals/sch/services/pcw/family_friendly.html

<http://www.uwhealth.org/childrens-hospital-guide/bill-of-rights-for-children-and-teens/12208>

http://www.thechildrenshospital.org/visit/patient_rights.aspx

Bill of Rights for Siblings

You have the right to:

Respect and Dignity

- We want to get to know you.
- We will tell you who we are, and we will call you by your name.
- We will take time to listen to you.
- We will honor your privacy.
- We will honor you/your family's beliefs and practices.
- You have the right to your own life and identity outside of your sibling's illness. You cannot compensate for your sibling's illness with high expectations for yourself.

Information You Can Understand

- We will work with your family to explain what is going on in our family. You have the right to be told the truth about CF in words I can understand.
- You can ask questions if you don't understand what is happening to your sibling and family.
- We will provide someone who speaks your language to help explain things to you.
- Information about you and your family will not be given out without you or your parent's permission.

Quality Collaborative Health Care

- You can know all the people who are a part of your family's healthcare team and ask for help or guidance from any them.
- Your ideas and feelings about how you want to be included in your siblings care are important.

Care that Supports You and Your Family

- All families are different. We want to learn about what's important to you and your family.
- You deserve to be your own person and not have responsibilities for yourself or siblings that are beyond your abilities.
- It is OK to have your own needs, even if they do not seem as important as your sibling's needs. It is OK to take a "time-out" from CF without being disloyal.
- We will work with your family to develop and maintain open and healthy communication.

Emotional Support

- Dealing with CF can bring up a lot of different emotions. You have the right to feel whatever you feel, not what someone says you should feel, and the right to express your feelings.
- It is OK to cry or complain or laugh.
- It is alright to appreciate your own good health without feeling guilty. It is not your fault your sibling has CF.
- It is normal to have fights from time to time with a sibling, even if he or she has CF. You can feel angry with someone and not always feel guilty, because sickness does not stop someone from being a real person.
- We can help you communicate with other siblings and families who have had experiences like yours.
- You can talk with people who know how to help when you have questions or problems.
- We will consider all your interests and needs, not just those related to your sibling's disease.

Adapted from:

<http://www.sixtyfiverosesthebook.com/the-well-sibling-bill-of-rights>

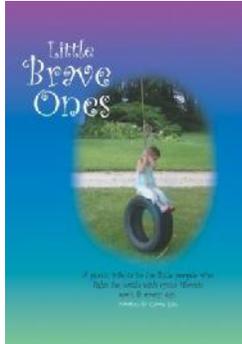
http://www.centracare.com/hospitals/sch/services/pcw/family_friendly.html

<http://www.uwhealth.org/childrens-hospital-guide/bill-of-rights-for-children-and-teens/12208>

http://cancerfamilycare.org/index.php?option=com_content&task=view&id=32&Itemid=66&PHPSESSID=e39cd7b4d1e92e6132a894445faf891f

Resources for Patients and Families

Books For Children

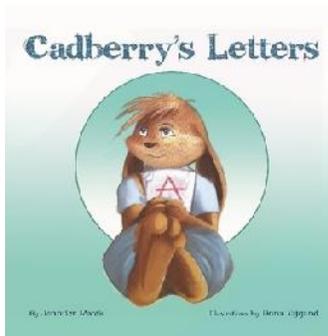
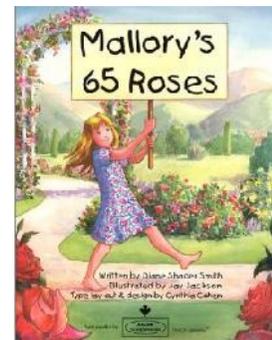


Little Brave Ones: For Children Who Battle Cystic Fibrosis by Carrie Lux

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 pre-schooler with CF.

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.

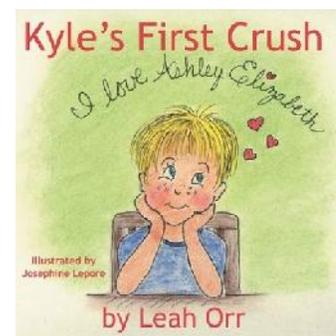


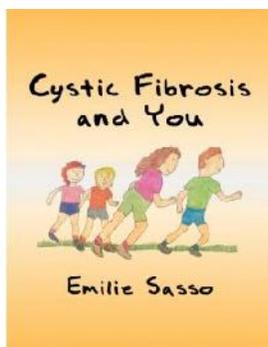
Cadbury's Letters by Jennifer Racek

Cadberry's mom is very forgetful. Every time 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.

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. You will enjoy this very endearing and uplifting love story.





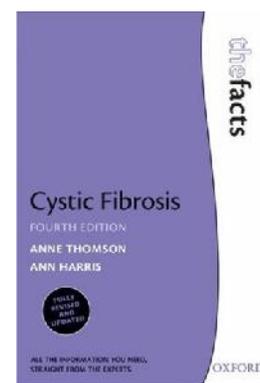
Cystic Fibrosis and You by Emilie Sasso

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.

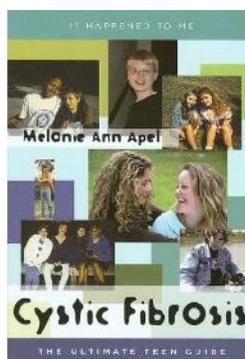
Books for Teens

Cystic Fibrosis (Facts) by Ann Thomson 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.



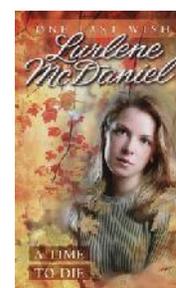
Cystic Fibrosis: The Ultimate Teen Guide by Melanie Ann Apel



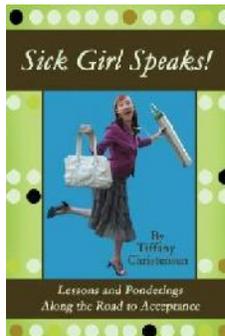
A solid introduction to the disease – the facts, the challenges, the complications, and the outlook for the future. Based on a series of interviews with young people with CF and their family members, the day-to-day dealings of life as a cystic fibrosis patient are described, including: who gets the disease 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 people, now in their 30s and 40s, having CF 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.

A Time to Die (One Last Wish) by Lurlene McDaniel

Sixteen-year-old Kara Fischer has cystic fibrosis and only months to live. But the close-knit bond she develops with Vince, who also has the disease, helps her come to terms with her own illness. Given one last wish, Kara wonders if miracles could really happen.

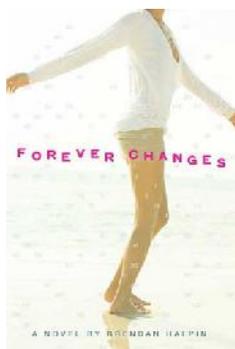


Sick Girl Speaks!: Lessons and Ponderings Along the Road to Acceptance by Tiffany Christensen



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

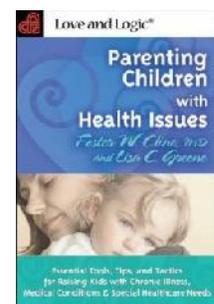


Brianna, a high school senior, lives with her dad and has two popular best friends. A verifiable math wizard, she is sure to be accepted at MIT. She also has CF. The death of Molly, a friend who also had CF, haunts Brianna and she fears that she will be next. With her body slowly failing her, she sometimes 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.

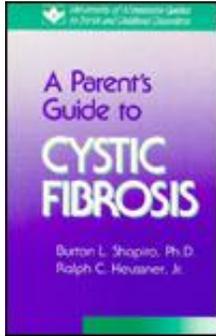
Books for Adults

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 needs. Whether your child struggles with allergies, asthma, diabetes, cystic fibrosis, an eating disorder or any other health issue, 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.



Parent's Guide to Cystic Fibrosis by Burton Shapiro

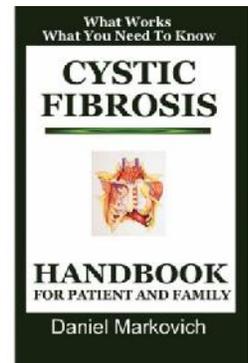


Explains in detail the genetic causes and biological effects of cystic fibrosis as well as its social and psychological ramifications. The authors describe how the body's various systems—respiratory, digestive, reproductive, and musculoskeletal—respond to the disease, and they discuss the rationale behind 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.

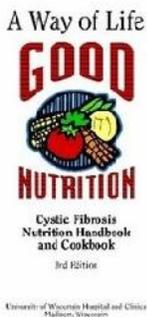
(http://www.upress.umn.edu/Books/S/shapiro_parents.html)

Cystic Fibrosis: Handbook for Patient and Family Edited by Daniel Markovich

This one-of-a-kind guide offers clear explanations and real-world advice on cystic fibrosis and its management. Here you'll find 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



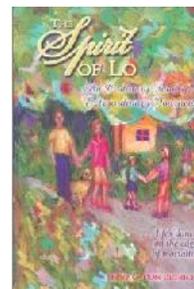
This handbook and cookbook is designed to help explain how CF affects the human body, and it explains the role diet plays in managing the disease. The initial sections of the handbook describe the challenge of eating enough of the right types of food to support growth and development, fight infections and lead a productive life. These sections are followed by 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 individuals with CF and their families and by University of Wisconsin Hospital and Clinics Clinical Nutrition Department. These easy-to-prepare, appealing foods can help add necessary nutrients and good taste to diets for people with CF.

The Spirit of Lo: An Ordinary Family's Extraordinary Journey by Terry &

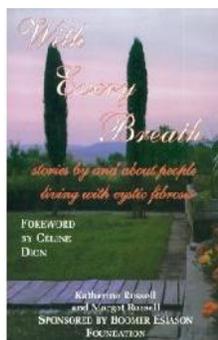
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Don Detrich

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.



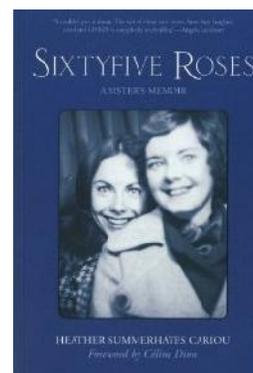
With Every Breath: Stories By and About People Living with Cystic Fibrosis by Katherine Russell and Margot Russell



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.



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.



<http://www.reachingoutfoundation.org/>

Cystic Fibrosis–Reaching Out Foundation, Inc. provides financial and educational resources to assist the needs of cystic fibrosis patients and families. The Reaching Out Foundation provides emergency funds, insurance assistance, nutritional assistance, and a quarterly education newsletter.



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.



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.

Examples of CF Educational Interventions

Parents of Newly Diagnosed Infants & Toddlers



Typically, infants will visit the CF clinic every one to three months during the first year of life, and begin quarterly visits around age 2. Parents need to be educated on the importance of enzyme replacement therapy (ERT), reaching optimal body mass index (BMI), and beginning chest physiotherapy (CPT). This is usually performed manually on infants, with the vest machine being introduced in toddlerhood.

Image: <http://health.usnews.com/health-news/best-hospitals/photos/cystic-fibrosis-close-up-and-personal/4>

- **Enzymes** – An informational booklet on enzyme replacement therapy (ERT) created by the Parent Advisory Council (with the assistance of the dietitian and Child Life Specialist) and will be given to each parent of a newly diagnosed infant. Additionally, the nutritionist or Child Life Specialist will demonstrate the technique of opening the capsules and helping the parent feed the enzymes to the infant during the first clinic visit.

(See Attachment A for informational booklet)

- **Manual & Vest CPT** – The respiratory therapist or Child Life Specialist will model proper CPT technique using percussion cups and open hands with drainage positions on a doll. Parents will be asked to demonstrate understanding by performing on the doll or infant. Parents are also encouraged to perform on each other to overcome the fear of hurting the child with too much pressure. Parents will receive a set of infant percussion cups and an informational brochure.

(http://www.pedilungdoes.com/education/cpt_infant.pdf)

Pre-School Age Child



As children reach preschool age, they are usually able to begin pulmonary function tests (PFT's) and start to learn to swallow pills (enzymes and vitamins). Both children and parents need to be educated on the proper techniques of PFT's. Parents should be given instructions on how to introduce and support the mastery of pill swallowing.

Image: http://www.pmh.health.wa.gov.au/services/respiratory_medicine/fot.jpg

- **Pulmonary Function Test (PFT's)** – The respiratory therapist and Child Life Specialist will explain the pulmonary function tests in developmentally appropriate language at the beginning of the clinic visit in the Child Life Center. The child life specialist will provide the patient with a marshmallow shooter and marshmallows and the respiratory therapist will ask patient to practice taking a deep breath and exhaling as quickly and as hard as possible. Target marks will be placed on the floor to measure the distance the marshmallow shoots. The respiratory therapist will then place a clip on the

child's nose and ask them to try to shoot the marshmallow as far as possible. The Child Life Specialist will give tickets based on the distance. Next, the Child Life Specialist will give a non-latex balloon and the respiratory therapist will ask the patient to practice taking normal breaths and then a deep breath and blowing the balloon up slowly but as big as possible. The Child Life Specialist will measure the balloon after each attempt and again give out tickets based on the size of the balloon. The child will be able to choose prizes based on the number of tickets received.

- **Pill Swallowing** – The Child Life Specialist will work the parent and child in the Child Life Center to teach the concept of pill swallowing at each visit during the child's 3rd year (if this task has not already been accomplished). During the first visit, the Child Life Specialist will hold a "tea party" with the patient and dolls. The Child Life Specialist will have an enzyme bottle filled with play enzymes (empty enzyme capsules filled with candy nonpareils). The Child Life Specialist will engage in imaginative play with the child and demonstrate feeding of a baby using nonpareils and enzymes. The Child Life Specialist will also model pill swallowing and assess the child's interest/readiness in attempting to repeat this behavior. On the second visit, the Child Life Specialist will play a game of Hungry Hungry Hippos with the patient and refer to the balls as enzymes and ask the child if they think they can swallow as many enzymes as the hippos in the game. On the third visit, the Child Life Specialist will introduce the pill swallowing kit to the parents and invite them to assist with Phase 1 in the Child Life Center. Some patients may successfully complete the entire program in one visit, others may need to continue through the program at home. Encourage the parents to continue reinforcements until the behavior is well-established.

(<http://rileychildrenshospital.com/resources/documents/CFPillSwallowingBrochure.pdf>)

School Age Child



As children reach school age, entry to school and adjustment to a new routine can create many psychosocial issues, such as self-esteem and the responsibility of self-care at school. Children are now able to receive more information about how their body works, the effects of CF, and the purpose of treatments. They can also begin to perform a greater portion of self-care in relation to respiratory therapy.

Image: <http://health.usnews.com/health-news/best-hospitals/photos/cystic-fibrosis-close-up-and-personal/3>

- **Nebulizer Breathing Treatment** – The Child Life Specialist will work with the child in the Child Life Center and engage the child in medical play with a teddy bear or medical doll, nebulizer, and various medications (saline labeled as medications). Child Life Specialist will ask the child to show how the teddy bear/doll does nebulizer treatments. As the child goes through the routine, the Child Life Specialist will interject to correct incorrect information and to introduce/expand on knowledge of body systems, functions, disease, and treatment purpose and routine. The Child Life Specialist will follow up on the next visit with a game of Nebulizer Dominoes to reinforce the proper information/steps to performing the nebulizer treatment/order of medications.

(See Attachment B for dominoes tiles)

- **Airway Clearance** – The Child Life Specialist and respiratory therapist will work with the Child Life Center will engage the patient in a variety of activities designed to teach airway clearance techniques. The first activity will be a straw painting exercise. The patient will use a straw to blow bubbles into a special formula of paint and soap to create bubbles and touch paper to the bubbles to make prints. The Child Life Specialist will explain how breathing into the straw against the pressure of the thick paint is actually helping to create a small backflow of air that pushes back into your lungs and helps to open your airways, making it easier for the mucus to be cleared. The respiratory therapist will explain that huffing is huffing is a forced breathing technique that allows gently squeezes the airways to move the mucus up and through. The Child Life Specialist will give the analogy of squeezing a tube of toothpaste near the top (coughing) which only gets a little bit of toothpaste out versus squeezing down low and gently squeezing while working your way up to the top (huffing). Huffing allows you to clear more mucus up because you are gently working it up from the bottom of your lungs. The respiratory therapist will then teach the huffing technique to the patient. The child will be asked to blow bubbles into the paints, make a paper print from the bubbles, then perform huffing. The Child Life Specialist will then help the patient make a take-home Bubble PEP device.

Adolescent



Adolescence brings the difficult issues of independence, sexuality, and body image. The transition to the adult CF team as the taking the primary role for their own airway clearance and managing food and enzymes. Puberty brings along changes to the body and often the beginnings of CF-Related Diabetes (CFRD). Many experience their first hospitalization for a “tune-up” during this period and may have their first experience with intravenous antibiotic therapy.

Image: http://www.oumedicine.com/images/OU_Physicians/Childrens/hematology_12_md.jpg

- **CF Related Diabetes & Nutrition** – The Child Life Specialist and dietitian will work with the patient in the Child Life Center to explain CFRD by using a model of the digestive system, a Hoberman sphere insulin/glucose model, and a poster of the diabetic food pyramid. The nutritionist will explain give the patient a personalized CFRD journal that contains the patient’s caloric intake needs and the carbohydrate limits based on the patient’s insulin dosage. The journal also contains daily glucose monitoring and food diaries, target ABC levels, healthy recipes for CFRD, stories from other teens with CFRD, tips for eating out with friends, and pages with prompts for journal entries. The Child Life Specialist will then introduce the Carbohydrate Cards deck and play a game of “Carb-Jack” with the patient. The game is based on the blackjack concept, except the “bust” number is the carbohydrate limit for the patient before additional insulin is required and the deck of cards contains food groups instead of suits and pictures of foods with the carbohydrate count for that food item.
- **PICC Line Antibiotic Therapy** – The Child Life Specialist will work with the patient in the Child Life Center to discuss upcoming hospitalization and the need for antibiotic therapy (sputum culture, low PFT’s, exacerbations, etc.). The Child Life Specialist will make explain the PICC line procedure (using verbiage found online at <http://www.thefurrymonkey.co.uk/picc.htm>) and invite patient to practice inserting a

PICC line using the “Trying it on for Size” shirt (t-shirt with printed circulatory system). With the line “in place”, the CLS will engage the patient in some movement activity by playing an active Wii game and discuss perceived and real limitations of having the PICC line in place.

Siblings/Children of Adults with CF



Well siblings and children of with CF are not without the need for educational and emotional support. Many will experience feelings of anxiety, frustration, anger, guilt, and confusion over the disease, treatments, and effects on the body. It is important to remember the needs of this special group and provide developmentally appropriate interventions such as medical play and expressive therapies.

Image: http://farm2.static.flickr.com/1282/1360554648_93b9708013.jpg

- **Hospitalization** (to older school aged children)– The Child Life Specialist will introduce a game of Apples to Apples (with special cards made to describe the sights, sounds, people, equipment, etc. in the hospital with definitions as in the style of the cards in Apples to Apples Junior edition) to the siblings in the Sibling Support group. The Child Life Specialist will supervise the game play, answering questions and clarifying misconceptions while engaging in dialogue with players as the adjective cards are played. After the game is played, the Child Life Specialist will give each sibling a special Going to the Hospital activity book designed for siblings. In this book will be word searches, picture Sudoku, dot-to-dots, medical maze, and other pencil/paper games. There will also be suggestions and tips to help the sibling cope and express his/her feelings and ideas for how to support the hospitalized sibling.
- **G-Tube** (to preschool aged children) – The Child Life Specialist will work with the sibling in the Child Life Center. First, the Child Life Specialist will read the book *When Jeremy Jones’s Stomach Stopped Working* to the sibling. After the Child Life Specialist finishes the story, she will engage the sibling in medical play with the sibling performing G-tube surgery on a doll/stuffed animal to reinforce the information covered in the book and to clarify any misconceptions/misunderstandings the sibling may have. The sibling will be allowed to keep the doll/stuffed animal.
(<http://www.mitoaction.org/pdf/bookGTube.pdf>)

Developmental information adapted from:

http://www.dhmc.org/webpage.cfm?site_id=2&org_id=370&morg_id=0&sec_id=0&gsec_id=38958&item_id=38961

What is CF?

CF and the Respiratory System

CF and the Digestive System

Pre-School	What is CF?	CF and the Respiratory System	CF and the Digestive System
School Age	<p>Cystic fibrosis (usually called CF for short) is a disease that causes the body to make thick, sticky mucus. Mucus is the sticky, slimy stuff that's made inside your body. Runny noses are really just noses with mucus coming out. Mucus in your body acts sort of like oil in a car's engine – it keeps everything lubricated and helps things move through your body. In kids with CF, this thick, sticky mucus usually causes problems in two major areas: the lungs and the digestive system. This is why people with CF cough a lot and have to take enzymes to help their stomach digest the food they eat. CF is a disease that you are born with – it is not something that you can catch by being around others with the disease.</p>	<p>Healthy lungs produce mucus, which protects the airways and makes it easier to breathe. But for a person with CF, the mucus is thick and sticky can clog up the lungs. This creates a place where bacteria can easily grow – and bacteria cause infections. People with CF usually cough a lot to clear mucus out of their lungs. Sometimes someone helps break up the mucus and shake it loose by clapping on the person's back. Some people wear a vest that helps to do the same thing. People with CF also do breathing treatments with a nebulizer machine, which takes liquid medicine and vaporizes it so that it can be breathed directly into the lungs. Breathing treatments also help by adding moisture and delivering medicine into the lungs. Breathing treatments help by adding moisture and delivering medicine to thin the mucus and fight infection into the lungs. A person who is trained in helping people breathe better, called a respiratory therapist, can help teach people with CF to do special breathing exercises that help get rid of extra mucus.</p>	<p>The airways and lungs are not the only thing affected in a person who has cystic fibrosis. Mucus-producing cells line the digestive tract, including the stomach, intestines, liver, and pancreas. The pancreas produces enzymes that help digest food and hormones that help absorb sugar. When thick mucus in the pancreas clogs up the narrow passageways, it can make it difficult for people to digest food and get all the vitamins and nutrients they need. Because the pancreas is not working properly, it can't deliver the enzymes needed to break down protein and fat in food. This is why people CF take enzyme pills with their meal to help digest their food. Some vitamins, like A, D, E, & K can only be absorbed by the body with fat, so people with CF may also take vitamin and mineral supplements to give their body the nutrients it needs to grow..</p>

	<i>What is CF?</i>	<i>CF and the Respiratory System</i>	<i>CF and the Digestive System</i>
<i>Adolescent</i>	<p>CF is a genetic disease that affects the body's epithelial cells, which are found in many places, including the sweat glands, the lungs, and the pancreas. In a person who does not have CF, the epithelial cells produce a thin, watery mucus that acts like a lubricant and helps protect the body's tissues. In a person with CF, an error in these cells causes problems with the balance of salt and water in the body. The body responds by making thick mucus. The thicker mucus doesn't move as easily, blocking the lungs and sometimes other ducts and passageways, causing infections and breathing problems.</p> <p>The two organs that are most affected are the lungs and pancreas, where the thick mucus causes breathing and digestive problems. The thicker mucus has trouble moving out of the lungs, so bacteria can remain and cause infections. The thick mucus can also be found in the pancreas — an organ that produces proteins called enzymes that flow into the intestine to support the body's digestion process. Because the mucus can block the path between the pancreas and the intestines, people with CF have trouble digesting food and getting the vitamins and nutrients they need from it.</p>	<p>To loosen mucus, people with CF exercise regularly and may use inhalers (like people with asthma use) or nebulizers that help deliver medication to the lungs.</p> <p>Coughing helps people with CF clear the mucus from their lungs. They may also take antibiotics to prevent or fight lung infections. Chest physical therapy may also be an important part of a person's CF treatment routine. After lying down in a position that helps drain mucus from the lungs, the person may have someone, like a parent, bang on his or her chest and back to loosen the mucus. Many people with CF now use a therapy vest that shakes the chest allows them to be more independent by doing their therapy on their own.</p> <p>Despite all of the efforts to clear the thick mucus from the lungs, bacteria may still get trapped inside the mucus. This means that people with CF get frequent lung infections that can damage their lungs over time. Sometimes these require strong antibiotics along with stays, or “tune-ups” in the hospital.</p>	<p>The thick, sticky mucus in someone with CF can also keep the intestines from absorbing important nutrients like fat and vitamins from food. This means that people with CF may be short and underweight for their age, and they may get sick a lot because their bodies can't fight infections well.</p> <p>About 85% to 90% of CF patients have pancreatic insufficiency. This means that the body doesn't pass certain chemicals, called enzymes, from the pancreas into the intestines properly. These enzymes are necessary for a person to digest fat, starch, and protein.</p> <p>People with pancreatic insufficiency need to take prescribed enzymes with meals and snacks to help them digest their food properly and get the nutrition they need to grow and develop. Enzymes need to be taken with every meal and most snacks. They should not be chewed or crushed up, and the dose should only be adjusted by the dietitian or doctor. People with pancreatic insufficiency might have problems with growth and weight gain, and they might also have frequent and bad-smelling bowel movements.</p> <p>As people with CF grow older, they may also develop other illnesses, such as diabetes (a disease in which a person's blood sugar is too high) or osteoporosis (a weakening of the bones). People with CF also need extra calories and nutrients to help them fight infection and keep their lungs strong, particularly if they get sick with colds or the flu. With the right balance of nutrition, extra fat and calories, and prescribed supplements, though, people with CF can keep themselves healthy.</p>

Adapted from <http://www.kidshealth.org>

Creating a Parent/Caregiver Support Group

Studies show that support groups can help most parents and caregivers of children with CF to better cope with their situations. Gathering with others who share their experiences also helps parents and caregivers define their roles in the healthcare process, improve their self-management skills and feel better about caring for their children.

The goals of a parent/caregivers support group are three-fold:

- Linking parents and caregivers who share a common experience
- Offering support for day-to-day issues and more stressful times
- Decreasing isolation while offering hope

The parent support group is guided by the needs of the parents and caregivers and supported by the care center. Monthly educational meetings are held on topics voted on by the group members. The Child Life Specialist and Social Worker attend the meetings and assist the group in locating expert presenters on desired topics.

One-to-One Support – Parents and caregivers can receive personal support, particularly during stressful situations, from mentor parents who understand what they are facing. Chosen by the healthcare staff, the diverse mentor parents receive training in listening and other communication skills.

Quarterly Newsletter – All families connected to the care center receive a quarterly parent-to-parent support newsletter. Created with a parent/caregiver perspective, the newsletter provides uplifting stories, updates, self-management skills and tips to help parents and caregivers feel motivated and successful.

Social Functions – Twice a year, parents and caregivers come together to share their experiences, strengths and hope. Parents and caregivers connect with others to escape isolation and frustration while learning about successful care strategies.

“We Remember Together” Memorial Program – To acknowledge the loss of loved ones to CF, network members plant a tree of the family’s choice at their home. The tree is a symbol to celebrate the life of the loved one, provide compassion and reduce feelings of isolation.



Image: http://www.murraystate.edu/Libraries/Interior_Content_Page_Background_Images_800x228/guygirlclass_800x228.sflb.ashx

Adapted from:

<http://www.cff.org/LivingWithCF/QualityImprovement/ImproveYourCare/ParentNetwork/>

Sample Activity for Parent/Caregiver Support Group

How to Partner with Professionals

Purpose:

Create strategies with parents that they can use while working with professionals in order to achieve outcomes for their children.

Objectives:

1. Determine and define top three to five situations in which parents need to utilize partnering strategies.
2. Discuss ways in which to turn challenges into successes
3. Define the role and rights of parents while partnering with professionals.

Agenda:

Introductions and Opener: 15-20 minutes

Each participant introduces themselves (remind folks to use first names for HIPAA purposes) and describes a situation in which they have to partner with professionals (examples: Doctor appointments, Social Workers, Psychologists, Nurses, Dietitian, Teachers, etc.)

Facilitator: Probe for details about what makes these situations challenging such as their perceptions about attitudes, feelings of being overwhelmed, intimidated. Discuss and support participants in their feelings and discuss that it is possible work with professionals even with these feelings and develop outcomes together.

What works?: 15-20 minutes

Facilitator: Divide participants into pairs and give each pair flip charts and markers. Ask participants to list what has worked for them in dealing with professionals. Probe for preparing a list of questions, expectations, knowing what their rights were, advocacy skills, and knowledge of a grievance procedure. Discuss strategies.

Developing Action Plans: 15-30 minutes

Facilitator: Assign each group a situation and provide pens, paper. Direct them to develop an action plan containing strategies and techniques that were discussed. Share handouts reflecting these strategies.

Debrief and Summarize: 15-20 minutes

Action Plan Handout

1. What situation is this action plan for?
2. Who will be attending?
3. What is the reason for the appointment/meeting?
4. What do I want to get done at this appointment/meeting?
5. What questions do I have?

Source: <http://cdd.unm.edu/ec/resources/pdfs/PSN/ParentSupportManual.pdf>

Creating a Sibling Support Group

Brothers and sisters will have a life-long and ever-changing need for information about their siblings' illness, treatments, and prognosis. The ideal peer group serves to both support and educate siblings by providing participants with kid-friendly information about a wide range of topics from guest speakers, tours, discussions, etc.

There are five main goals of a successful sibling support group:

1. To provide brothers and sisters of CF patients an opportunity to meet other siblings in a relaxed, recreational setting.
2. To provide brothers and sisters with opportunities to discuss common joys and concerns with other CF siblings.
3. To provide siblings with an opportunity to learn how others handle situations commonly experienced by other CF siblings.
4. To provide siblings with an opportunity to learn more about the implications of their sibling's condition and treatment.
5. To provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by CF siblings.

Ideally, at least one of the group facilitators will be an adult sibling. If this is not possible, seek a parent who can offer advice, provide a family perspective, and help you spread the word about your program. The Child Life Specialist and Social Worker should also serve as co-facilitators for the group. Family participation and parent education can be achieved through hosting bi-annual meetings for parents and caregivers of the participants in the sibling group.

Sibling group participants should be given some say about group activities, especially for the older school age and adolescent participants. Facilitators should continually seek input and feedback about activities they liked and disliked and ideas that they have for recreation, discussion, and informational activities.

Sibling Teddy Bear Clinic – Twice a year, the Child Life Specialist and other clinic staff will hold a “Teddy Bear Clinic” to educate siblings on CF, procedures, and treatments.

Social Outings – Four times a year, siblings will have a chance to attend a social outing with other CF siblings. Members of the sibling group will enjoy a chance to engage in typical peer-to-peer friendship building and recreational play without the structure of the group activities.

Community Service – Many siblings powerless regarding their brother or sister's illness. The sibling group helps empower them by providing community service opportunities for siblings to get involved in fundraising and outreach programs.



Image: <http://knol.google.com/k/-/-/232p4eed9p5ya/bu9o73/homeschooling-support-groups.jpg>

Adapted from: <http://www.siblingsupport.org>

Sample Activities for Emotional Expression in a Sibling Support Group

Emotional Symphony: Participants are divided into two groups. One group will play the audience and the other the performers in the emotional symphony. Performers line up side-by-side and face the audience. The facilitator will conduct the participants performing in the symphony. Ask the audience for some emotions that siblings dealing with a brother or sister with cystic fibrosis may experience and write them down. It is good to get a range of contrasting emotions for the players to use. Assign one emotion to each performer in the symphony. Once each player is given their emotion the conductor points from one player to another. The players do not speak, but express their emotions through physical movement and noise. The intensity of the emotion is increased as the conductor raises her hand while pointing at the player. The conductor moves from player to player conducting an emotional symphony.

Questions Darts: The group begins by brainstorming a list of positive coping strategies. Next, the facilitator will explain that they're going to play a very special game of darts that will help them talk about ways to manage and deal with stress.

Game Rules:

- Players take turns standing behind a tapeline and throwing child-safe darts (foam, suction cup, or Velcro ball) at a target on the wall.
- The player's score is recorded.
- The player then draws a card from the question deck.
- The player may choose to answer the question, pass, or ask for help from the group.
- The game ends when all of the question cards have been answered or pre-determined time limit expires.
- The player with the most points can open up the gift bag, reads the message to the group, then passes out the prize to the rest of the group.

*From: Creative Interventions for Troubled Children & Youth
by Liana Lowenstein*

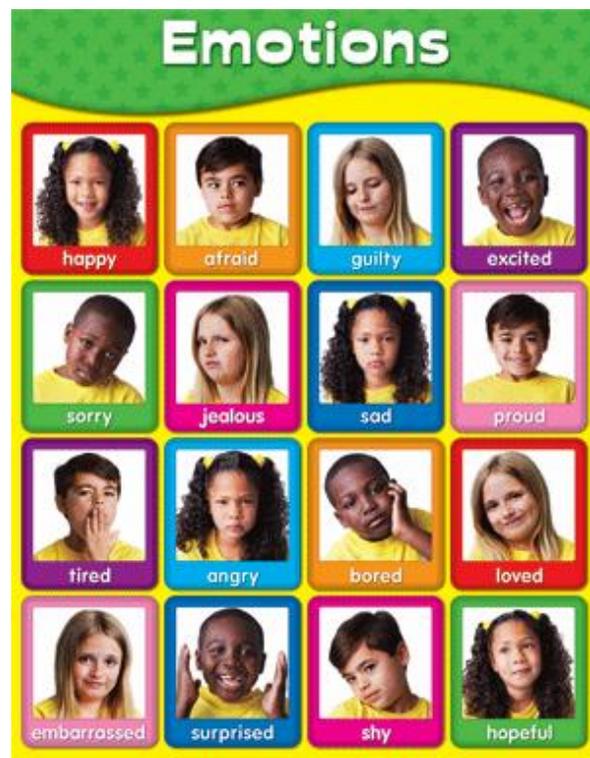


Image:
http://sushantskoltey.files.wordpress.com/2010/04/cd114055_emotions.gif

School Entry & Re-Entry Programs

Studies have shown that children with chronic diseases and conditions experience gaps in services related to their education. Some of these gaps identified include:

- Poor communication between healthcare providers and school staff
- Lack of information on specific illnesses for staff when children returned to school
- Frequent and/or intermittent absenteeism
- Inadequate home instruction
- Lack of educational support
- Poor identification of special learning needs
- General lack of educational service coordination



The American Academy of Pediatrics (AAP) has issued several policy statements on the education of Children with Special Health Care Needs (CSHCN), calling for physicians to attend to their patients' educational needs.

Key Components of a School Entry/-Re-Entry Program

- **Parent Education:** The Child Life Specialist is the contact person for the healthcare team. When a child is about to enter school, the Child Life Specialist will re-introduce educational support services. The Child Life Specialist should develop a parent information packet, which includes a parent consent form and any pertinent medical documentation that is necessary for their child to return to school and explain to the family what a school entry/re-entry program is and how it can be tailored to meet the needs of their child. Let parents know that entry/re-entry services are optional and that decisions to utilize the services can be made at any time. With cystic fibrosis, school entry/re-entry services may be needed at different critical points in the child's education or following changes in medical status. Discuss with parents the federal laws as they relate to education and the rights of CSHCN. Collaborate with the social worker to identify resources for additional services.
- **School Entry/Re-entry Team:** Establish a multidisciplinary school entry/re-entry outreach team that includes education, medical and psychosocial staff. To begin, contact the school and establish a collaborative relationship by identifying the education, medical and psychosocial staff who will continue to care for the child within the school and hospital. Parents should be included on the team to support family-centered care.
- **School Entry/Re-entry Plan:** Facilitate discussions between the family and the healthcare team regarding the child's needs during the school day, and help to develop a plan to discuss with the school team. Parents are the experts in knowing their child's needs, and as such, they are a critical part of healthcare team who must be involved in the development of their child's school entry/re-entry plan. Work with the family to design a school entry/re-entry visit such as a presentation to the child's class or an in-service for the faculty, and may even include parents of classmates.
- **Required Health Documentation:** Check again before the child begins school or is discharged to see if the school requires any medical documentation to facilitate the entry/return to school.

- **Siblings:** Recognize and acknowledge sibling issues and the need for support. Let the parents know that a child life specialist is available to provide sibling support.
- **School-Health-Parent Task Force:** Child Life should coordinate a School-Health-Parent Task Force which includes several staff members from various disciplines, staff from local school districts, and parents from various districts. It is always helpful to have a physician and local state representative on your task force.¹

Tips for Teachers of Students with Cystic Fibrosis²

CF is not a common chronic illness in children, it is possible for a teacher to have a student with CF in their classroom, or at least in their school. Common issues that arise in the classroom include:

- **Coughing:** Some children with CF have a chronic cough. Coughing is good because it helps the child to clear the lungs of the thick mucus and defend against lung infections. Teachers can help by encouraging coughing and not making the child feel uncomfortable for having to cough in class. Remember, CF is not contagious and a child with CF needs to cough.
- **Restroom Breaks:** Because of the digestive symptoms of CF, teachers can help by letting a child with CF leave class at any time to use the restroom. Have a private talk about this with the child to help avoid any embarrassment.
- **Medicines:** Most children with CF need to take medicines at school. The most common medicine is supplemental pancreatic enzymes. Children must take their enzyme pills right before any time that they eat. This includes snacks, lunch and special parties where food is served. Teachers can help by making sure children take their enzymes with all meals and at the right time. Other medicines a child might take include antibiotics, breathing treatments or anti-inflammatory medicines. Teachers can also help by working with parents, health professionals and other school staff if other medicines are needed from time to time.
- **Physical Education/Sports:** Exercise helps people with CF maintain stamina and keep their lungs clear. However, CF may decrease a student's tolerance of physical exertion. Compared to their peers, children and teens with CF may not have the same level of endurance. Teachers can help by working with students on an activity plan that meets their needs for exercise while not overdoing it. Remember, if a child coughs during exertion, it is not harmful. Allow the child enough time to finish coughing and then have them begin exercising again.
- **Absences:** A severe lung infection can cause a child to miss up to 3 consecutive weeks of school. Children often have to be in the hospital to receive antibiotics by IV. Some children are able to receive antibiotic therapy by IV at home with the help of home healthcare services. Teachers can help by sending assignments home and communicating and working with home tutors or teachers in the hospital. They can also work with the child after their hospital stay to come up with a plan for catching up with schoolwork.

¹ http://www.childlife.org/files/Summer_2005_Bulletin_-_FINAL.pdf

² <http://www.seattlechildrens.org/pdf/PE646.pdf>

- **Peer Relationships:** Some children with CF may look smaller and thinner than their peers. They also may not be able to be as physically active, have more school absences, have a chronic cough and take medicines. All of these aspects of having CF differ from healthy peers. Teachers can help by being knowledgeable about CF and working with students, peers, and families to address problems with peer relationships.,
- **Academic Performance:** Students with CF should be given the same academic program as their peers. They can perform at the same level as other students. Intellectual impairment or other academic problems are not a direct result of having CF. However, in some cases, the impact of a chronic illness – such as fatigue, absences and the effects of decreased lung function over time – can affect a student’s academic performance. Teachers can help by working with a student who is feeling ill or fatigued to individualize academic expectations. This is often referred to as an individualized education plan, or IEP. A 504 Plan is a plan that can provide accommodations for absences, etc., without changing academic expectations. Teachers can also assist by giving guidelines and encouragement for school work during times of school absences and hospital stays. Students with CF should be expected to learn and be encouraged to make the most of going to school.

Common Symptoms of Cystic Fibrosis³

Symptom	Cause for Symptom
<i>Fatigue</i>	<i>Thick mucus in lungs makes it hard to breathe</i>
<i>Stomach Aches/ Loose Stools/Bloating</i>	<i>Malabsorption</i>
<i>Cough</i>	<i>Lungs need to clear mucus in order to keep infections low</i>
<i>Shortness of breath or wheezing</i>	<i>Thick mucus in lungs makes it hard to breathe</i>
<i>Headaches</i>	<i>Frequent sinus infections</i>
<i>Blowing nose frequently</i>	<i>Frequent sinus infections</i>
<i>Need for high salt, high fat, high calorie foods (taken with enzymes)</i>	<i>Body doesn’t absorb food/vitamins properly – needed to keep energy levels to their maximums and leads to better CF (health) , academic and psychosocial outcomes</i>
<i>CF Related Diabetes</i>	<i>Pancreas doesn’t provide enough insulin to body</i>
<i>Seizures</i>	<i>Salt depletion in body</i>

Treatments for Cystic Fibrosis

(Treatment at home varies from 1 ¼ hours to 3+ hours/day)

- Chest Therapy
- Enzymes/Vitamins
- Inhaled medications (breathing machine)
- Antibiotics, anti-inflammatories, expectorants
- High calorie meals and snacks
- Intermittent hospitalizations for up to 2 weeks at a time

³ <http://www.cysticfibrosisidaho.org/d/content/helpful-information-schools>

Things to Watch For Between Peers

- Comments at school relating to student’s weight (IE: “Are you anorexic?”, “I wish I could eat like you and stay so skinny...”)
- Teasing about being short or skinny
- Teasing about being slow athletically
- Teasing/questions about taking “pills” (enzymes)
- Teasing/questions about having a G-Tube (for feeding/nutritional needs)

Accommodations for Students with Cystic Fibrosis

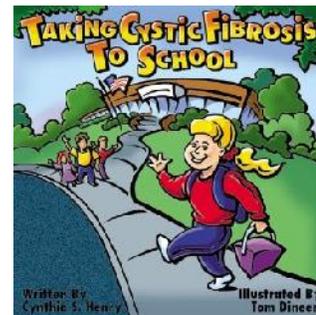
Reason for Accommodation	Suggested Accommodation
<i>To maintain/increase weight for optimal health</i>	High calorie diet (lunch/snacks)
<i>Maintains energy/stabilizes weight</i>	Extra snacks/supplements
<i>Maximize time for eating all food needs to be consumed</i>	Ability to be first in line at lunch
<i>Exercise will help lung health</i>	Participate in PE to level of ability
<i>Need to keep body well hydrated</i>	Water bottle on desk
<i>Decrease self-consciousness so that they will cough to clear lungs of excess mucus</i>	Designated place to cough/blow nose
<i>Digestive issues associated with CF</i>	Open pass to bathroom
<i>Privacy due to odor associated with digestive issues</i>	Open pass to use nurse’s bathroom
<i>Due to missing school /instruction time for medical reasons</i>	Extended time to make up work/take tests
<i>Due to need for treatments and eating before school day</i>	Ability to have a “late start”
<i>To maneuver building due to decrease energy</i>	Early release from class
<i>Alleviates problem of gathering books when an absence is unexpected</i>	Second set of books for home
<i>To aide in food/snack consumption</i>	Adjust school regulations to allow Student to keep enzymes on person
<i>Student may be hospitalized or at home for medical reasons</i>	Plan for school absences (work, materials, instruction)
<i>Absences due to hospital stays, medical appointments or home IV treatments</i>	Homebound services/Intermittent HB services
<i>To be preventative in case of need</i>	Emergency Medical Plan-to include contact information
<i>To bring awareness and understanding to school on CF and CF related issues</i>	Peer education on CF (with student/family permission)

Sample Classroom Presentation for Pre-K/Kindergarten

Suggested Reading:

Taking Cystic Fibrosis to School by Cynthia S. Henry

In this book, Jessie discusses her condition, cystic fibrosis, with her classmates. Even though she has cystic fibrosis, she can still attend school and do many of the same things her classmates do. Includes 'Ten Tips for Teachers' and 'Kids Quiz'. Part of the Special Kids in School series. Ages 5-10.⁴



Agenda:

- Use the classroom script prepared by Lisa Greene to introduce the topic of CF.⁵
- Further explain what CF is using the language for pre-school/school-age children. (See Educational Interventions Section).
- Give a visual for how bacteria can stick to the mucus in the lungs:
Materials: 3 plastic trays/shallow plastic containers containing each of the following: water, honey, and candy sprinkles
 1. Place one hand in the water tray - this is the mucus in healthy lungs
 2. Place second hand in the honey tray - this is mucus in CF lungs
 3. Ask class what they think will happen if germs were to get into the lungs.
 4. Dip both hands into tray of candy sprinkles and say that those sprinkles represent the germs that we breathe in from the air and that germs get stuck in the mucus in CF lungs, where they grow and make people with CF sick.
- Continue reading developmentally appropriate language to effect on digestive system
- Return to the script prepared by Lisa Greene to explain treatment & common CF issues
- Add that coughing is a way for kids with CF to clear the mucus out of their lungs. Also add that you cannot catch CF.
- Distribute materials found on Lisa Greene's webpage.
- Allow children to make their own mucus.

Recipe:

1 cup water

2 cups cornstarch

Food coloring (your choice: green or yellow)

Procedure:

Step 1: Pour cornstarch into a bowl.

Step 2: Slowly add water, just a bit at a time, mixing with fingers as you go until smooth.

Step 3: Add just a few drops of food coloring to add real slime appeal.

Step 4: Mixture will appear solid/hard after created, but pick it up and let it ooze!

<http://www.asthmacamps.org/asthmacamps/toolkit/AnatomyActivities.asp>



⁴ <http://www.nprinc.com/kids/tcfs.htm>

⁵ <http://www.happyheartfamilies.com/ClassmateTeaching.html>

Bill of Rights for a Student with a Cystic Fibrosis

- Parents/guardians and students have the right to privacy in accordance with HIPPA
- A student has the right to perform or have blood testing done in the classroom if preferred by the parent/guardian.
- Parents/guardians have the right to be informed of test results, such as blood glucose levels, or any incident that occurs.
- Students have the right to not report self-test results to the nurse unless the parent/guardian requests they do so.
- Students have the right to have a school nurse who is up to date on current protocols and best practices (especially for Diabetes) as per the Nurse Practice Act.
- Students have the right to have their provider's orders followed. If a school nurse does not understand them, they should contact the provider to clarify.
- Students have the right to attend school, regardless of whether or not they are independent in their medical regime.
- A student has the right to an IEP or 504 if their chronic medical condition impacts their learning. This decision is made by the CSE or 504 team.
- A student with a chronic disease has the right to an emergency care plan if their condition could result in a significant or life-threatening event.
- Parents/guardians have the right to not inform the school of their child's medical conditions, and/or medications taken at home by their child.
- Parents/guardians have the right to require their permission in order for school personnel to discuss their child's medical condition with their private provider.
- A student with a chronic condition has the right to have an escort if they need to be sent to the nurse.
- Parents/guardians have the right to provide the school with safe food alternatives for their child (such as for a party, or snacks).
- Students with documented medical need have the right to have food or drinks in classroom. A school can request an order from the student's provider.
- Parents/guardians have the right to not be required to designate a parental designee in order for their child to attend a field trip.
- A student who has a medical need that can only be performed by licensed personnel has the right to appropriate medical accommodations and/or personnel on a field trip. If none are available to attend the field trip, then the trip must be cancelled. A student cannot be denied a field trip that other students attend because of the lack of appropriate medical accommodations and/or personnel.



Adapted from:

<http://www.schoolhealthservicesny.com/files/news/SED%20Bill%20of%20Rights%20final.pdf>

Incorporating Child Life into the Clinic Environment

The Child Life Specialist will be an integral part of the Cystic Fibrosis Center clinical team. As a member of the psychosocial team, the Child Life Specialist will work closely with the Pediatric and Adult Social Workers to assess the need for child life services and implement a plan of care for any pediatric patient, sibling, or child of adult patient seen in the clinic. The Child Life Specialist will report to the Center Director.

In order to create a physical environment that demonstrates support for the patients and families seen in the Cystic Fibrosis Center, the Child Life Specialist makes the following recommendations for various rooms in the clinic.

Entrance/Waiting Room

- Use walls as interactive murals to provide peer-to-peer support, such as “Helping Hands”, “Coping Chain”, “Feelings Forest”, “What ‘Bugs Me’ about CF”, “Rings of Prevention”, and Apple Action Pick
- Lower the counters at reception desk/nursing station to eliminate unnecessary territorial markers.
- Install a fish tank to incorporate nature into the space and allow for some of the benefits of animal therapy

Exam rooms

- Ability to control lighting
- Ability to allow for supportive presence of family members and CLS
- Body Systems Vinyl Wall Stickers with removable parts
- Medical Play & Activity Kits, such as “Make Mucus”, “Bronchial Binoculars”, marshmallow shooters, bubbles, straw soccer games, tissues/scarves, spirometer game, kazoos, non-latex balloons, straw painting, stickers and markers for mask decoration, CF word game and coloring activity books, “All About Me” sheets,
- Place/toys for movement and exploration during wait times – infant/toddler rooms
- Music (CD Player/iPod Dock)

Family Resource Library

- Computers
- DVD/VCR with educational videos available for checkout
- Educational Pamphlets/brochures
- Books on CF, chronic illness, coping, stress management, chronic illness, child development, school issues, legal issues, sibling support, and grief and loss

Child Life Center

- Medical Equipment – Nebulizer, Vest, Play Spirometer, Toy Medical Kits
- Play Kitchen & Food Items
- Medical Dolls & Puppets
- Arts & Crafts Supplies

Outdoor Space

- Tribute Rose Garden
- Labyrinth
- Wind Chimes
- Interfaith Prayer Space



Image:

<http://www.johnsoncitypress.com/images/Photos/Articles/large/ChildrensHospitalpatient121510.jpg>

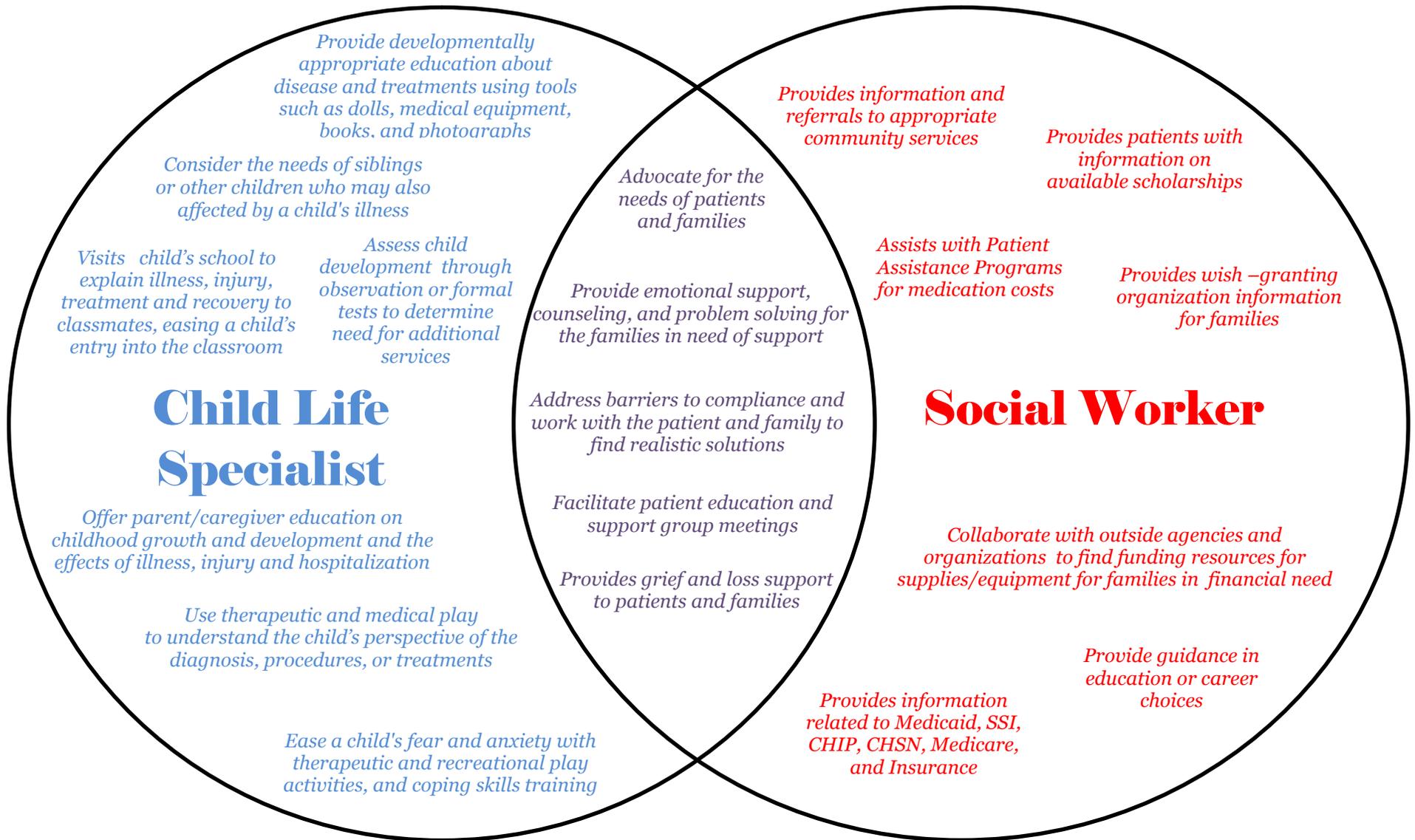
Inter-Disciplinary Collaboration & Professional Development

As a member of the Cystic Fibrosis Center team, the Child Life Specialist will collaborate with all members of the staff to provide the best quality of care for patients and families. The Child Life Specialist will participate in weekly center staff meetings to discuss patient cases to be seen in the upcoming week, research team meetings, psychosocial team meetings, and Grand Rounds. Additionally, the Child Life Specialist will have the opportunity to serve on various committees, such as Parent Advisory Council, Bereavement and Memorial Planning Committee, Resource and Planning, and the Patient Hero of the Month Nomination Committee. The Child Life Specialist will continue to promote the field of Child Life by presenting educational sessions for medical/nursing students, at the Family Education Day, and at the North American Cystic Fibrosis Conference.

Although the field is expanding, the majority of Child Life Specialists still continue to work in a hospital setting and spend a large portion of their daily duties is the minimization of stress and trauma on hospitalized children by providing normalcy through play. This is most often achieved through the use of free play in playroom settings. For a Child Life Specialist in an outpatient clinic setting, the goal is still to minimize stress and trauma through play, but the focus shifts away from free play settings to more purposeful play opportunities to provide developmentally-appropriate medical education, preparation, and expression interventions. When the concept of Child Life is first introduced to the clinic, one of the main concerns among staff may be defining the role and scope of the Child Life Specialist and understanding the differences between a Child Life Specialist and a Social Worker. In order to clarify the roles of both and to emphasize the collaborative efforts of the two in order to provide possible psychosocial care, the Child Life Specialist and Social Worker will present a “Lunch and Learn” session on the topic.



Image: http://farm5.static.flickr.com/4139/4772248549_07f29a4abo.jpg



Adapted from:

<http://www.playworks.net/article-child-life.html>

<https://www.cookchildrens.org/SpecialtyServices/Pulmonology/Services/Pages/cysticfibrosis.aspx>

http://dhrdcap.co.la.ca.us/classspec/index.cfm?fuseaction=preview.detail&cs_id=4222

Who is A Child Life Specialist?

- A member of your child's cystic fibrosis health care team
- They understand how children develop, how family members interact, and how disease and medical experiences affect children and families
- Have experience in working with children of all ages and their families

How Can a Child Life Specialist Help You and Your Family?

The Child Life Specialist on the Cystic Fibrosis Team can help your child and family by:

- Explaining cystic fibrosis in a way your child can understand
- Using medical play to help your child learn about his/her treatment using tools such as dolls, medical equipment, books, and photographs
- Preparing and supporting your child before, during, and after medical procedures such as blood tests and immunizations and assisting with coping techniques (toys, books, guided imagery and relaxation techniques)
- Helping your child overcome challenges such as swallowing pills
- Providing therapeutic play opportunities (medical play) to understand the child's perspective of his/her diagnosis or treatments
- Helping your child find ways to safely express his or her feelings
- Helping your other children learn and express their feelings through play
- Explaining your child's needs to the other members of the health care team
- Performing developmental assessments, through observation or formal tests, to determine a need for additional services.
- Offering parent/caregiver education on childhood growth and development and the effects of illness, injury and hospitalization.
- Working with you and your child to help achieve developmental tasks related to self-care and transition to independence
- Visiting a child's school to explain illness and treatment to classmates, easing a child's transition from the hospital to the classroom.



For More Information or to schedule an appointment or to discuss services, contact Kirsten @ (404) 509-5000

Adapted from:

<http://www.hamiltonhealthsciences.ca/documents/Patient%20Education/ChildLifeSpecialistCysticFibrosisClinic-lw.pdf>
<https://www.cookchildrens.org/SpecialtyServices/Pulmonology/Services/Pages/cysticfibrosis.aspx>



Become a Magic Maker!

Help a child with cystic fibrosis transform their therapy vest into a magical machine.

Magic Makers is a volunteer-run community program that provides hope and self-esteem to local pediatric cystic fibrosis patients a cape or set of wings and a story book.

We are looking for talented and creative individuals and sewing groups to help us spread the magic!



For more information, contact
Kirsten@magicmakers.org





Fun with Food

*Having trouble finding ways to meet your
cystic fibrosis nutritional needs?*

Sign up for a "Fun with Food" session and
receive free in-home personalized cooking
lessons for the whole family

Learn how to:

- 🎯 increase caloric and vitamin intake
- 🎯 Manage CF-Related Diabetes through diet
- 🎯 Include the whole family in healthy eating habits

Lessons provided by Local food service professionals and culinary students. Ingredients and supplies are included. Meal Plans & Recipes created in conjunction with the dietitian.



For more information, contact Kirsten (Child Life Specialist) or Susan (Dietitian)

Sample Assessment Form

Child Life Developmental Assessment & Plan			
Patient:	Created By:	Date:	Time:
Michael Jones	K. Black	7/2010	11:15 AM
Developmental Age:	Coping:	Assessment:	
<input type="checkbox"/> Infant (0-12mos) <input type="checkbox"/> Toddler (13-35mos) <input type="checkbox"/> Preschool (3-5) <input type="checkbox"/> School Age (6-12) <input type="checkbox"/> Adolescent (13-19) <input type="checkbox"/> Chronological Age	<input type="checkbox"/> Approachable <input type="checkbox"/> Withdrawn <input type="checkbox"/> Responsive <input type="checkbox"/> Interactive <input type="checkbox"/> Seeks Support <input type="checkbox"/> Crying <input type="checkbox"/> Activity Level <input type="checkbox"/> Low <input type="checkbox"/> Medium <input type="checkbox"/> High <input type="checkbox"/> Distractibility <input type="checkbox"/> Easy <input type="checkbox"/> Moderate <input type="checkbox"/> Difficult	<input type="checkbox"/> Initial Needs Assessment <input type="checkbox"/> Routine Clinic Visit <input type="checkbox"/> Developmental Tasks Assessment <input type="checkbox"/> Developmental Risk <input type="checkbox"/> Disease Education Needed <input type="checkbox"/> Compliance Issues <input type="checkbox"/> Treatment Plan Support <input type="checkbox"/> Educational Services <input type="checkbox"/> Emotional Support <input type="checkbox"/> Family Support <input type="checkbox"/> Legacy Building <input type="checkbox"/> Grief Support <input type="checkbox"/> Other:	
DISEASE KNOWLEDGE: <i>Can the child and family, on a developmentally-appropriate level:</i> <input type="checkbox"/> Name the disease <input type="checkbox"/> Describe how the disease works <input type="checkbox"/> Describe the effects of the disease <input type="checkbox"/> Identify patient's current disease treatments <input type="checkbox"/> Discuss possible side effects of treatments <input type="checkbox"/> Describe the etiology of the disease <input type="checkbox"/> Understand the future expectations related to the disease <i>Behavioral Indicators:</i>			
ROLE IN TREATMENT <i>Do the child and family:</i> <input type="checkbox"/> Understand the need for treatment <input type="checkbox"/> Use coping skills effectively <input type="checkbox"/> Participate in self-care as appropriate <input type="checkbox"/> Receive opportunities for realistic choices <input type="checkbox"/> Know hospital routines <input type="checkbox"/> Adhere to treatment regimen <input type="checkbox"/> Include the child in decision-making as developmentally appropriate			

Behavioral Indicators:

INTEGRATION INTO NORMAL ROUTINES

Is/Are:

- The child exhibiting typical development and normal interests in play and socialization
- The child attending school when possible
- An appropriate education plan devised for patient in entry/re-entry to school
- Siblings included
- Role in family maintained
- Open communication exhibited in the family
- Limits and discipline maintained and consistent
- Roles, environment and/or activities modified as needed
- Roles in community maintained

Behavioral Indicators:

SUPPORT SYSTEMS IN PLACE:

Is/Are:

- Social support services, such as support groups, engaged as necessary
- Medical information communicated clearly (misconceptions clarified)
- Extended family educated about condition
- Peers/community educated about condition
- Opportunities for emotional expression and validation available
- Important relationships outside family maintained

Behavioral Indicators:

INTERVENTIONS / EDUCATION:

- Child Life Specialist provided medical preparation at patient's developmental level:
Describe:

- Patient participated in individual medical play session facilitated by Child Life Specialist:
Describe:

- Child Life Specialist provided coaching for comfort with patient and parent/caregiver:
 - During procedure
 - Prior to procedure
 - Following procedure/treatmentDescribe:

- Provided opportunities for expression of feelings related to disease/medical experience through:
 - Unstructured free play
 - Developmentally-appropriate expressive activities
 - Focused medical play
 Describe:

- Provided introduction/review of comfort management relaxation strategies (i.e. guided imagery, positioning, choices for coping)
 Describe:

- Child Life Specialist provided patient/family with educational resource materials related to disease and clinic experience and support services available in collaboration with medical team:
 Describe:

TREATMENT PLAN / FOLLOW UP:

- Will continue to follow as needed for child life services
- Will refer to/for:
 - Social work:
 - Dietitian:
 - Diabetes Educator:
 - Psychologist:
 - Other:
- Will continue to support medical team plan for patient compliance
- Will continue medical play interventions as needed to assist patient in understanding illness or upcoming procedures/surgery/hospitalization
 Describe:

- Continue to assess family needs for continued support (i.e. sibling(s), parent/caregiver)
- Recommended plan (describe) to patient/parent/caregiver for coping strategies at home
 Describe:

OUTCOMES:

- Increased knowledge of illness/clinic visit/procedures
- Maintained developmental skills
- Improved developmental skills
- Increased coping and adjustment

NOTES:

Adapted from:

http://www.med.umich.edu/mcit/carewebwe/help/cdoctemplates/Child%20&%20Family%20Life/8-16-10_Child%20and%20Family%20Life.htm; Thompson, R. (2009) *The handbook of child life: A guide for pediatric psychosocial care*. Springfield: Charles C. Thomas.

Sample Grant Letters of Inquiry

March 1, 2011

Mr. Grant Maker
Alliance Development-Patient Advocacy Grants
Novartis Pharmaceuticals Corporation
One Health Plaza, East Hanover, NJ 07936-1080

Re: Letter of Inquiry

Dear Mr. Maker:

Thank you for taking the time to visit the Cystic Fibrosis Center and discuss the implementation of child life services into our current psychosocial support services for patients and families. I sincerely appreciate your taking the time to learn about the field of child life and the ways in which child life services can benefit the patients and families seen at the center.

We are aware that the Novartis Pharmaceuticals Corporation distributes a number of grants for patient education and support program development purposes. We wish to apply for one of the Alliance Development-Patient Advocacy grants.

The Cystic Fibrosis Center has become a national leader in terms of quality services. Our patient data on lung function and nutritional status has consistently rated well above the natural average. Our transition program process that moves patients from pediatric to adult care has received national acclaim and become a model for other centers around the country. Recently, the Cystic Fibrosis Center launched a new effort to increase research on medical treatments and programming aimed at patient compliance.

I am pleased to write to you about a project that I believe will be of interest to the Novartis Pharmaceuticals Corporation. The Cystic Fibrosis Center is seeking \$150,000 over three years to provide child life services to the pediatric patients and youth members of our patient families, including siblings and children of adult cystic fibrosis patients.

We are seeking support from Novartis Pharmaceuticals Corporation to enable us to develop a pilot child life program and demonstrate its soundness and effectiveness to the funders, governmental health agencies, and local private funding sources for future funding of the long-term program.

We ask for your partnership because of your commitment to assisting organizations in their efforts to educate and support patients, caregivers, family members, and the public in areas of therapeutic interest of the public in areas of therapeutic interest to Novartis Pharmaceuticals Corporation, such as cystic fibrosis.

As the field of health-care embraces the concept of family-centered care, it is critical that we provide information and support to our young patients and their family members. We are seeking funding to establish a Child Life Center with the supplies, materials, staff support needed to provide medical and therapeutic play opportunities to enhance the understanding and coping of patients, siblings, and other members of the family. The Child Life Center will serve approximately 500 pediatric patients, siblings, and children of adult patients.

Thank you for your support and assistance to the Cystic Fibrosis Center, and the patients and families it serves. We look forward to your consideration of our request and the opportunity to submit a formal proposal for your review. We will be pleased to submit additional information at your request. Please do not hesitate to contact me at (404) 509-5000.

Sincerely,

A handwritten signature in black ink that reads "Kirsten M. Black". The signature is written in a cursive, slightly slanted style.

Kirsten M. Black
Child Life Specialist
The Cystic Fibrosis Center

March 1, 2011

Mr. Grant Maker
Atlanta Braves Foundation
Grants Program
755 Hank Aaron Drive
Atlanta, GA 30315

Dear Mr. Maker:

The Cystic Fibrosis Center is the leading provider of care to cystic fibrosis patients in the state. The Center also provides extensive patient and family education about the medical, genetic and nutritional aspects of cystic fibrosis. We are requesting your consideration of a proposal to expand the services available to the siblings of our patients with the development of a sibling support group.

We believe that supporting the siblings is vital to improving family coping, leading to improved patient treatment adherence, and ultimately improving health outcomes. Your foundation has expressed a special interest in the coordination of services to young people dealing with chronic health issues. We hope that you will give our project further consideration.

The sibling support program will provide siblings with the opportunity for respite from the demands of living with a sibling with cystic fibrosis. Siblings will participate in a wide variety of activities that encourage fun, adventure and leadership qualities whilst developing individual coping skills in a supportive and therapeutic environment. The children leave with an understanding that other children share similar issues in living with cystic fibrosis.

We estimate the cost of this project the first year at \$1,000 to educational and therapeutic activity supplies for monthly meetings, two "Sibling Day" workshops, a holiday party, and two recreational outings.

Thank you for your consideration of the project. If you have any questions, please feel free to contact me at (404) 509-5000.

Sincerely,



Kirsten M. Black
Child Life Specialist
The Cystic Fibrosis Center

Adapted from: <http://literacy.kent.edu/Oasis/grants/samplefoundation.html>

References

Child Life Specialist Responsibilities

<http://www.vcuchildrens.org/?id=780&sid=4>

<http://www.uihealthcare.com/depts/rehabilitationtherapies/childlifeprogram/goals.html>

<https://jobs-kennedykrieger.icims.com/jobs/7038/job>

http://beta.hrservicesinc.com/appone/branding/wvuh/MainInfoReq.asp?R_ID=459201&B_ID=20&fid=1&Ad=&CountryID=3

<http://cms.bsu.edu/~media/DepartmentalContent/FCS/PDFs/clshandbook.ashx>

Kirsten Black is a graduate student in the University of La Verne's child life master's program and an intern at the Emory Cystic Fibrosis Center. Over the past 12 years, Kirsten has been an active member of the cystic fibrosis community, first as a counselor at the former Cystic Fibrosis Camp of Georgia and then as a staff member at the Georgia chapter of the Cystic Fibrosis Foundation. An advocate of developmentally-appropriate disease education and staged transfer of responsibilities, Kirsten is focusing her current research and thesis on a evidence-based transition plan for self-care for clinicians and a companion document for parents, children and teens with educational information and suggested activities.