

LIFE AFTER THE DIAGNOSIS
a parent's guide to healthy living with cystic fibrosis

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WHAT'S INSIDE
Table of Contents

Chapter One - The Diagnosis p. 1-2

Chapter Two - Gaining Knowledge p. 3-4

Chapter Three - Living with CF p. 5-6

Chapter Four - Resources p. 7-8

HOW DO I GET OFF THIS RIDE?!

Riding the Emotional Rollercoaster of Your Child's Diagnosis

By Lisa C. Greene - mom of two kids with CF, author, public speaker and certified parent coach

Up and down, around and around, out of control and going wayyy too fast. That's how some parents describe how they felt when swirling around in the medical maelstrom that follows a child's diagnosis of cystic fibrosis or another serious medical issue.

That's how I felt when my son was born via caesarian section and whisked away into the Neonatal Intensive Care Unit (NICU) after three seconds of "bonding." I saw him just long enough to know that things weren't looking good. He had meconium ileus and was unable to breathe because of his severely distended abdomen. They wheeled me away to recover from my surgery and prepped him for his. Then came the words I'll never forget: "I am sorry, but your son has cystic fibrosis."

At age eleven, he is now doing great. His abdomen (and my heart) still bears the scars from that day. But I can say that, as impossible as it seemed at the time, life does get back to "normal." In fact, much of the time, life is downright good. At the beginning, it wasn't. That first year was really hard.

Experiencing Grief

When people suffer a loss, they go through a series of emotions. The stages of grief, first described by Elizabeth Kubler-Ross, are denial, anger, bargaining or questioning, depression and acceptance. As the parents of children with CF, we can expect to go through the grieving process several times throughout the course of their illness. Each new bit of "bad news" can bring us back to grief. This constant cycling through the grieving process is called "chronic grief" or "chronic sorrow."

It helps to understand that this is normal because otherwise, we might think we are going crazy! We can be happy one minute and bawling the next. Even though we might feel far from normal, these reactions are just a part of the process. The stages can come in any order; it's not a tidy, predictable process, and there is no telling how long any of them will last.

The journey to acceptance is a very individual, personal one. And of course our kids (both those with CF and siblings) will likely go through these stages, too. Here are some ideas for getting through the rough spots: Get positive support from others including within the CF community; focus on your faith; keep a journal or write a blog; read inspiring books by others who have gone before you; take time to do the fun things you love; indulge your five physical senses with things like natural beauty, music, massages, soothing smells or special foods. Simple things can make a big difference.

If you or your children are having a hard time working through these stages on your own--and are struggling with anger or depression-- get professional help.

Understanding Guilt

Guilt is another common emotion many parents experience. This is normal, too. However, guilt based in irrational beliefs can cause us to respond to our kids in unhealthy ways. Examples of the most common irrational beliefs:

It is my fault that my child got sick.

I must make sure my child is happy all the time.

It is my job to make my (older and capable) child stay healthy.

It is selfish or wrong to take time for myself.

The family is a mess and it's my fault. I need to try harder.

These irrational beliefs can cause all kinds of ineffective parental responses like failing to correct misbehavior, showering the child with material things, taking on all of the responsibility for an older child's medications, and not taking the time for good parental self-care.

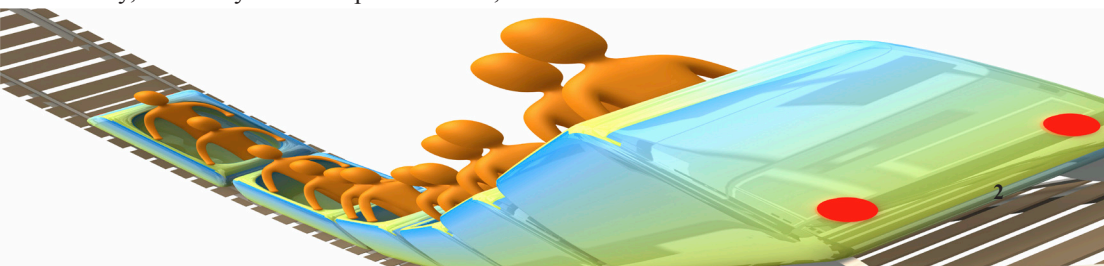
The major problem with guilt is that *when parents feel guilt, children respond with blame*. Feeling guilt is a way of saying "I am responsible." Then the child says, deep down inside, "Well, if *you* are responsible, then it must be *your* fault!" and blames the parent for whatever is going wrong. This does nothing for a healthy parent-child relationship. Nor does it move the child along on the road to personal responsibility. So, be aware of your feelings of guilt and the impact it can have on your parenting responses.

Different People Have Different Needs

Finally, be aware that people work through their fear, worry, guilt and grief in different ways. Some people want information, others don't. Some people reach out for support, others need solitude; some cry, others don't.

If you and your partner have different grieving styles, this can cause conflict. "He doesn't care" and "She's too emotional" are often heard by marriage counselors. There is no "right way" to grieve as long as you are able carry out your day-to-day responsibilities and maintain your relationships. Give yourself and your loved ones the time, space, and freedom to grieve in their own way. Good communication skills are essential.

The good news is that, just like a roller coaster, the "newly diagnosed" ride eventually slows down and stops. Even in the toughest of circumstances, life has a way of becoming routine. You will find a new "normal." And you'll be able to look back and say, "As scary as that experience was, I survived!"



LEARN THE LINGO

Understanding the Language of Cystic Fibrosis



Once you have entered the world of cystic fibrosis, you will come across a variety of terms in speaking with your doctors and in researching the disease. It is easy to be overwhelmed, confused and even scared by the amount of new language, but once you dig deeper, you'll be more comfortable. Here are a few terms that will soon be a part of your every day vocabulary:

ADEK - A vitamin taken for nutritional supplementation in individuals with deficient diets or difficulty in absorbing fat-soluble vitamins.

Bronchoscopy - A procedure that allows a doctor to look at an airway through a thin viewing instrument called a bronchoscope. During a bronchoscopy, a doctor will examine the throat, larynx, trachea, and lower airways. It is a good option for younger children who cannot produce sputum.

Chest Physical Therapy - (Also chest physiotherapy or CPT) Helps patients breathe more freely and get more oxygen into the body by breaking up lung secretions. CPT includes postural drainage, chest percussion, chest vibration using a mechanical airway clearance system called a vest, turning, breathing exercises, coughing, and incentive spirometry.

Clinical Trials - The study of new drugs that patients participate in to assess the drug's effectiveness. Clinical trials are essential in the development of new medications to treat cystic fibrosis.

Digestive Enzymes - (Also pancreatic enzymes) Digestive enzymes come in pill or capsule form and are taken by mouth. They work in the intestines to help digest food so it can be absorbed properly by the body. Brand names include Creon, Zenpep and Pancreaze.

FEV1 - (Forced Expiratory Volume in One Second) When measuring pulmonary function, this is the volume of air which can be forcibly exhaled from the lungs in the first second of a pulmonary function test. The number is expressed as a percentage of what the "normal" predicted value is for someone the same age, gender, body size and race.

FVC - (Forced Vital Capacity) When measuring pulmonary function, this is the volume of air which can be forcibly and maximally exhaled out of the lungs. The number is expressed as a percentage of what the "normal" predicted value is for someone the same age, gender, body size and race.

Gene Mutations - Any alteration in the inherited genotype (or genetic makeup). There are more than 1,400 different mutations of the CF gene. The most common CF gene mutation is $\Delta F508$.

Malabsorption - A clinical term that encompasses defects occurring during the digestion and absorption of food nutrients. CF patients do not properly absorb nutrients and fats due to pancreatic insufficiency.

Nebulizers - Inhaled treatments given by aerosol—a mist made from liquid medicines. The medicines go into a cup (nebulizer) that is attached to a small air compressor. The compressor blows air through the cup and makes a mist. The following are common medicines taken by nebulizer:

- **Albuterol and Ipratropium** - Work by different mechanisms, but both cause the muscles of the airways to relax, resulting in the lungs opening up. This prepares the lungs for the other medicines to work more efficiently.
- **Pulmozyme®** - Thins mucus by breaking down its DNA, enabling people to clear it from their lungs more easily.
- **Inhaled TOBI®** - (Tobramycin solution for inhalation) An inhaled antibiotic treatment that can be effective against the most common source of chronic lung infections, a bacterium called *Pseudomonas aeruginosa*.
- **Hypertonic saline** - Draws more water into the airways and makes it easier to cough out the mucus.
- **Colistin** - An antibiotic used to fight lung infections, particularly *Pseudomonas aeruginosa*. However, there is no research that shows it works or if it is safe.
- **Cayston®** - (Aztreonam solution for inhalation) An inhaled antibiotic treatment that can be effective against *Pseudomonas aeruginosa*. Unlike the medications above, Cayston is administered by an Altera® device.

Pseudomonas - A bacteria that is often found in the lungs of CF patients. *Pseudomonas aeruginosa* (PA) is the most common form of *pseudomonas* found in CF patients. It is treated with antibiotics.

Pulmonary Function Test - (Also called PFTs) A group of tests that measure how well the lungs take in and release air. For the test, you breathe into a mouthpiece that is connected to an instrument taking the measurements. For some of the tests, you can breathe normally and quietly. Others require forced inhalation or exhalation after a deep breath.

Sputum - The mucus and other matter brought up from the lungs, bronchi, and trachea that one may cough up.

Throat Culture - A test to find a bacterial or fungal infection in the throat. A sample swabbed from the throat is put in a special cup (culture) that allows infections to grow. If an infection grows, the culture is positive.

Tune-Up - (Also called clean-out) A round of intravenous antibiotics used to treat infections, or pulmonary exacerbations, administered at a hospital or at home. Tune-Ups often include increased airway clearance treatments and a focus on nutrition.

AVOIDING THE BUMPS IN THE ROAD: Essential Parenting Tips for CF Parents

by Lisa C. Greene - mom of two kids with CF, author, public speaker and certified parent coach

Parenting isn't for the faint-hearted! Raising kids throughout their developmental stages is tricky enough; parents of kids with cystic fibrosis have to face additional challenges along the way.

When we know where the bumps and potholes are, it becomes a lot easier to avoid them! So let's take a look at some of the challenges parents face when raising kids with cystic fibrosis and other medical issues. As you navigate family life with a child with CF, keep these tips in mind. They are in no particular order.

Treat your child with CF the same as your other children. People with CF are living longer, happy, rewarding, productive lives. They have families and careers. Don't let discouraging statistics cause you to lower your expectations. Set high (but reasonable) expectations for schoolwork, chores, sports, extracurricular activities and good behavior.

Model good problem solving, conflict resolution and coping skills. Children learn to cope with hard times by watching and learning from their parents. Parents who cope well, manage their frustration, communicate in healthy ways and express optimism are far more likely to raise kids who are confident, responsible, resilient, and hopeful.

Take good care of yourself. Not only is this important to avoid burnout but again, it sets the model for the children. This means that parents must take the time for date nights and self-care. This also means that parents do not tolerate disrespect from the children (or from each other). They set healthy boundaries around the many demands that come with raising a child with special healthcare needs.

Learn effective parenting skills. It is crucial that parents of kids with CF have good, effective parenting skills to rely on. There is no substitute for knowing how to defuse an argument, setting limits without causing power struggles, sharing control in appropriate ways, engaging in mutual problem solving and properly communicating about difficult issues. Nagging, yelling, bribing, threatening, and lecturing are not effective in the long run, especially where medical adherence issues are concerned.

Do your best not to show frustration. Of course you will feel frustrated over and over again on your "parenting journey." And that's just fine! We're all human. The trouble starts when we show it with anger, threats, warnings, and nagging. Charles Fay, PhD of Love and Logic® says, "Anger and frustration fuel misbehavior." So learn how to respond appropriately in frustrating moments. Everyone will be happier and more relaxed, especially you!



Make sure your child has accurate, age-appropriate information about CF. Give honest answers laced with hope when asked difficult questions. Your child will pick up on your emotions--both positive and negative--so be sure to get your own feelings of worry and fear under control before you discuss difficult issues with your child.

If your child doesn't ask questions about CF, take the initiative to teach about CF including the possible consequences of poor self-care. At some point, your children will stumble across difficult information and it's best if they've heard it from you first; presented matter-of-factly, lovingly and optimistically.

Don't make your child with CF the focal point of the family. Your child is a part of the family, not the family. Don't define or label yourselves as parents of a child with a chronic illness. We are all people first, with hopes, dreams, fears, needs and gifts.

Don't overcompensate for feelings of guilt. Keep your home a "guilt free" zone. Some parents try to "make it all better" with material things and not setting limits when it is appropriate to do so. This creates more problems in the long run.

Do not overprotect your child. Don't limit the activities of a healthy child with CF. Telling otherwise healthy children or teens with CF (mild to moderate lung involvement) that they "can't" do something because they have CF is the number one way to invite rebellion or depression down the road, especially if the forbidden activity is a popular one like swimming, playing outside, going on play dates, or visiting the playground.

Transition begins when your child is old enough to spit peas from the highchair! Transition is the process of preparing your child for independence in the real world. Many parents think that the teen years are the time to begin transition, but it is best to start much earlier. Even two-year-olds can make simple choices around their medical requirements. Transition isn't an event; turning eighteen is. That's when your child will move into the adult medical system and be expected to take full responsibility for his or her own care. However, your child needs to learn good health habits and personal responsibility much earlier. So start early! The earlier you start shifting the responsibility for good self-care in small, age-appropriate doses, the more prepared your child, and you, will be for the big event: the 18th birthday party!

Focus on thankfulness and the positive. Nurture a spirit of respect, cooperation and appreciation for each other and the blessings that are present in all of your lives. Make it a habit to count your family's blessings together each day: jobs, a roof, food, good doctors and medications, advances in medical research, freedom, friends and family, compassion, love, faith, and hope. Always focus on hope. Because:

"Hope sees the invisible, feels the intangible, and achieves the impossible."

ADVICE FROM OTHER PARENTS

Insight and Encouragement From Parents Who Have Been There

You are not alone in navigating this disease; many parents have travelled this path before you and are happy to help you through their experiences. You can find some of their words of wisdom below:

Don't believe everything you read - Information found on the internet and in text books can often paint a very grim image of cystic fibrosis. Be sure to read this information knowing that cystic fibrosis looks different for each patient and is a lot less frightening in daily life than books and articles make it sound. *-Tricia, mom of 6 year old with cystic fibrosis*

CF is a manageable disease that you have control over - Through advancements in medicines, treatments and procedures, CF has become a very manageable disease. It is crucial to realize that the more committed you and your child are to healthy living through treatments, exercise, and a positive attitude, the healthier your child will be. *-Dan, dad of 13 year old with cystic fibrosis*

Your child will adopt your attitude about CF - Attitude is everything. If you have a positive, healthy, encouraging perspective about life with cystic fibrosis, your child will adopt the same attitude. This attitude will become essential when you and your child are faced with difficult situations and circumstances. *-Christine, mom of 29 year old with cystic fibrosis*

Good parenting skills are essential - Raising a child with CF takes special parenting skills! Empower your child to cope well with life by responding positively and purposefully to the challenges that are an everyday part of being a parent. You can do it! *-Lisa, mom of two children with cystic fibrosis*

Don't be afraid to ask questions - If your doctors are unclear, if you don't understand what you're reading, if you don't know how to do something; ask! Doctors, CFF chapters, online forums and sites, and CF parents are all happy to share any information they have. *-Matthew, dad of 2 year old with cystic fibrosis*

Diet and exercise are crucial - While diet and exercise are important for all of your children, they are even more crucial for your child with CF. Exercise promotes good lung health by increasing lung capacity and forcing your child to cough, clearing mucus from the airways, while a well-balanced, high-calorie diet is essential for proper physical development and weight gain.

-Nancy, mom of 4 year old with cystic fibrosis



ADDITIONAL RESOURCES

Valuable Online Resources for Information and Encouragement

There are many useful and encouraging Web sites that you can visit to get information about cystic fibrosis and living with CF. These are sites that we recommend you visit to find facts, comfort and friendship. Be sure to check out any medical advice with your doctors *before* putting it into practice.

www.ParentingChildrenWithHealthIssues.com - Discover the skills to raise happy, healthier children with CF. Free video, audio, and other resources provide effective, practical tools to empower, motivate and communicate with children of all ages. Based on the popular Love and Logic® parenting program (www.loveandlogic.com).

www.CysticLife.org - A social network providing the CF community with peer-generated tips, information and encouragement with access to blogs, forums, reviews and user profiles, as well as the ability to directly communicate with other members.

www.TipsForCFParents.com - Provides tips and resources for parents of children with CF. Lisa C. Greene is the mom of two kids with CF, a parent coach and co- author with Foster Cline, MD of the award-winning *Parenting Children with Health Issues*.

www.BloomingRoseFoundation.org - The Foundations' mission is to provide social services, positive contacts and hope to families immediately after diagnosis.

www.cff.org - The Cystic Fibrosis Foundation (CFF) provides information about living with CF, treatments and research. The CFF assures the development of the means to cure and to control CF and improve patient's quality of life.

www.CFLiving.com - An educational site that offers information and support for those living with or caring for someone with cystic fibrosis. It is designed to help you work more closely with your Care Team, learn about treatment options, and provide interactive educational resources.

www.cfri.org - CFRI's mission is to fund research, provide educational and personal support, and spread awareness of cystic fibrosis.

www.CFvoice.com - An online community for those living with cystic fibrosis. A place for motivation, inspiration and connection to the CF community.

www.CysticFibrosis.com - An online community offering tools and resources for Cystic Fibrosis.

www.cystic-L.org - A free email service dedicated to the exchange of information and support specific to cystic fibrosis.

www.Esiason.org - The Boomer Esiason Foundation is a dynamic partnership of leaders in the medical and business communities joining with volunteers to heighten awareness, education and the quality of life for those affected by CF.

www.Facebook.com - This internationally known social network is used by many CF-related organizations and community members to share information and encouragement.

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