

CARING FOR YOUR TODDLER AND PRESCHOOLER
a parent's guide to healthy living with cystic fibrosis

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AGES AND STAGES: WHAT MAKES TODDLERS TICK?

By Lisa C. Greene - mom of two kids with CF and parent educator and Foster W. Cline, MD - child psychiatrist and co-founder of Love and Logic®

Charles Dickens wrote in *A Tale of Two Cities*: “It was the best of times and it was the worst of times...” The same could also be said about the toddler years! This is a time of discovery, wonder, unbridled joy, excitement about life, and unparalleled cuteness. This is also the time for stupendous tantrums, never-ending messes, demands, epic power struggles, and fits of all kinds. It all comes in the same, small package.

Effective parenting skills are essential. The forming of self concept starts here and will impact self care and attitude throughout your child’s life. Many of the behavioral challenges parents have with their adolescents are rooted in parenting responses during these early years. And the teen years can be especially problematic when a child has CF. So let’s take a brief look at some early childhood basics so that we can hopefully prevent problems down the road.

The Foundation of Discipline

Most mothers naturally handle tiny infants with “good enough” parenting. They are able to feed, cuddle, and change their baby. It is when toddlers develop their own curiosity about the world, want to explore it, and begin to develop a mind and intentions of their own that unaware parents start to lose the discipline and respect of their children. Depending on how they themselves were parented, the media, and other social influences, parents might be uncertain of how to effectively handle the tantrums, demands, and no’s of these years.

During this time, when discipline falters, children can become very difficult and the parents soon grow weary. Adding the presence of CF compounds the problem. Food issues are common with all toddlers but can be particularly exasperating when a child has CF and is low on the growth chart.

During the second year of life, children must learn the foundation upon which all discipline is based which is *Come, Sit, No, Go, Stay*: “Come here.” Sit there.” “No.” “Go over there.” “Stay right here.” When three-and four-year-old children respond (and it doesn’t even have to be respectfully!) to “come, sit, no, go, and stay” parents are more likely to have an easier time with discipline over the years.

The Role of Parental Power

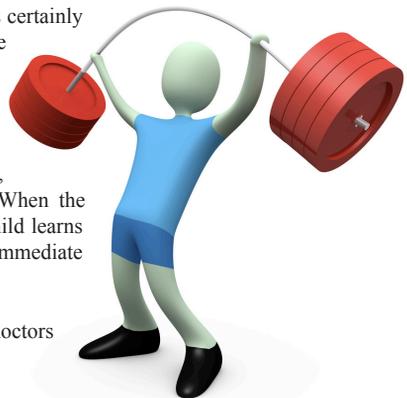
The fact that parents have the power and may use it is seldom openly discussed but let’s look at this issue carefully. Children who have adequate parenting learn the following important life-lessons during the second year of life:

- Parents say what they mean and mean what they say
- Parents have the power
- Parents love them and would rather not use power
- Parents are willing to use power only when necessary

Child development experts talk about the second year of life as the time of life that individuals learn “autonomy and independence.” This is certainly true, but what experts sometimes neglect to say is that “response to authority” is the other side of the same coin. Every armed service teaches: “You can’t give orders until you first learn to take orders.”

As children respond properly to parental structure and limits, parents give progressively more independence and freedom. When the child comes when called, he can play on the lawn. When the child learns not to run in the street, the child can play further away from the immediate presence of the parent.

Having respect for authority is critical. Parents, teachers, and doctors



are all important authority figures that will shape a child's life. Children who learn how to get along with authority figures will have a much easier time at home, in school, and in the medical system.

As parents, we want to raise kids who see us as both powerful and loving. Most parents have the loving part down. It's the power they have trouble with. They tend to be either too hard or too easy on the child. So, how do parents effectively show infants and toddlers they have the power? Early on, it is physical responses carried without shows of anger and frustration:

- They are carried to their crib or playpen for a "time out".
- They are lifted up and put down whether or not they like it.
- They have their diapers changed no matter how they kick or arch their little backs.
- When illness is present, they get their medications even when they resist.
- When disobeying the command "Don't touch" parents remove the child's hand, remove the object or, if necessary, remove the child.

These physical responses say, "Honey, you have to do it my way, I have the power." And these responses must be delivered lovingly, calmly, and matter-of-factly: "Ohhh. I know you don't want a bath, sweetie, but that's not a choice. Here we go." And the parent gently dips the child in the bath and quickly washes him despite the fussing. *Effective parents use loving actions and few words rather than lots of words and no action.*

The Power of Example

Since young children reflect their parents' emotions, wise parents model the emotions and behaviors they want their children to show. The problem is, when parents are dealing with the stresses of life with medical issues, the emotions that they model might not always be happy ones! Therefore, developing good stress management and coping skills is essential. Also, using effective parenting skills will help you reduce frustration and feel confident about handling discipline challenges.

Taking good care of yourself is especially important during these early years. It's also the hardest because toddlers are time consuming and work intensive. The presence of medical issues makes it even more challenging. Getting support from others- family, friends and community- is critical.

Teach About Medical Adherence Early

Toddlers and preschoolers learn about the world primarily through exploration, play, manipulative touch (like blocks), and pictures. Now is the time to start teaching your children about their bodies, the importance of good self care, and begin laying the foundation of CF education that you'll build upon over the years to come. Start with picture books like *Cadberry's Letters*, *Little Brave Ones*, or *Taking Cystic Fibrosis to School*. Draw your own pictures together of good bugs battling the bad bugs. Use silliness and fun to help young children comply with their medical requirements.

Choices work especially well during these years. Use choices instead of demands and commands especially around medical requirements: "Would you like to do your breathing treatments now or in ten minutes?" "Would you like your pills with white or chocolate milk?" "Would you like to color or play with stickers while you do your vest?" Be excited about your child's good choices. Show lots of emotion when things go well and very little emotion when they don't.

Of course, these years are filled with many No's- coming from both the adults and their kids! Learn to reword your phrases so you don't use 'No' too often. Example: Child says, "Can I have a cookie?" It's natural to say, "No. We're about to eat dinner." But you'll probably get a fight. Try this instead: "Sure! You may have a cookie right after dinner- which will be in ten minutes."

Believe it or not, toddlers grow up and start school! And this rite of passage brings a new batch of joys and challenges. You might even surprise yourself by wishing for the days when they were little so enjoy this special time while you can.

ENZYMES BEYOND APPLESAUCE:

How to Teach Your Preschooler to Take Enzymes

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

Your toddler is changing and growing up right before your eyes! He or she is becoming more independent, capable, and wants to do everything him or herself. “No! ME do it!” becomes a common refrain during the two’s and three’s.

Wise parents use this independent streak to their advantage! Even though it takes more time, allow your toddler to help you as much as possible with chores, cooking, getting dressed *their* way, and taking medications. Parents don’t realize that when they tell their toddler, “No, I’ll do it” they are training them *not* to be helpful, independent, and responsible down the road. Taking the time now to encourage independence will save you time, effort, and possibly heartache later.

Using choices for this age group is a critical parenting skill- especially around medical management. Choices will promote your toddler’s independence as well as help avoid power struggles before they occur: “We need to do your breathing treatments this morning before we leave. Would you like to start them now or in five minutes?” Most kids say: “Five minutes!” After the time is up, say: “Five minutes is up so it’s time to start your breathing treatments. Would you like to push the buttons or have me push them?” Of course your toddler will say, “Me! Me!” Then follow up with even more choices like, “Do you think you can keep the mask on or would you like me to hold it?” “Would you like to watch Dora on TV or color her picture?” You get the idea...

One of the “rites of passage” for children with CF is swallowing pancreatic enzymes whole instead of opening capsules and sprinkling beads on the spoon with applesauce. Many parents are surprised at how young their child can actually do this. I know we were with our own two children.

We discovered by accident that our son Jacob was ready. I had left some empty enzyme shells on his high chair tray after opening them up for the applesauce and he started playing with them. Then, of course, they ended up in his mouth. We realized, “Hey! This kid might be able to take them on his own!” So, then we tried putting the whole enzyme right on top of the applesauce and it all went right down the old hatch! Then, we tried putting the enzymes along with some cheerios on his tray and he just popped them into his mouth.

Jake was three years old when he started taking enzymes on his own. With our daughter, we tried this process a little earlier and she was able to take them around age two and a half. By the time both kids were in the first grade, they were chucking down a handful of enzymes and other pills with no problem.

Lots of praise, excitement, and enthusiasm is the key to encouraging children to try swallowing the enzymes whole. Also, say the word “enzymes” once they start taking the capsules so they learn the proper term from the beginning. Our kids were so cute; they both called them “Zen Zimes” for a long time. If your child doesn’t cooperate, don’t get frustrated or impatient. Just stay calm, matter-of-fact and say, “Okay, all done. We’ll try again later.” And just move back to an easier method, such as swallowing the beads in apple sauce.

If your child does not spontaneously learn to swallow pills, ask your CF team for help. A behavioral intervention was developed by Alexandra Quittner, PhD and Kristen Marciel, PhD. This intervention



teaches children to swallow pills by practicing with small candies and eventually swallowing their enzymes. It is recommended that you ask your CF Team about this program and use this approach with the assistance and supervision of your CF Team.

Parents often ask: what age should I start this? Of course it depends on your child. Some kids have a hard time taking pills even when they are teenagers! I've also heard of children as young as eighteen months of age taking enzymes whole. Personally, I think around three years of age is a good time to give it a try with the help of your CF Team.

If my kids could take their enzymes by age three, then it's possible your child can, too!

TEACHING YOUR PRESCHOOLER ABOUT CF

By Lisa C. Greene and Kirsten Black, MS

The way that preschoolers think and process information is very different from adults. Their emotions can affect their ability to think and understand. The Preschool Thinker* is:

- Magical- Unable to explain how things happen in a logical, step-by-step process.
- Perceptual- Dominated by what he sees, hears, feels or smells.
- Egocentric- Able to see the world from his point of view only.
- Immediate- Focused on the present only.
- Absolute- Tends to see everything in extremes; sees few relationships.

Things you can do with preschoolers to help them learn about CF:

- Read children's books together about the body in general and about CF care.
- Watch videos together about the body in general and CF care (see www.TipsForCFParents.com for links to child-friendly CF video clips).
- Teach basic outer body parts including tummy, chest, arms, legs, etc. Four- and five-year-olds can start to learn about internal organs like lungs, heart, stomach, intestines. Provide simple descriptions and make the explanation relevant to experiences the child can feel/see/touch. Example: Have the child blow up a balloon, then let them feel the air rush out of the balloon. Explain that the lungs are like balloons inside our body that take in fresh air (blowing up the balloon) and then trade it for used air (the air escaping from the balloon).
- Allow your child to participate in CF care in little ways with your help. Some ideas: Push buttons on machines, put on vest and clip the buckles, pick out foods from two choices, help hold mask during treatments, sprinkle opened up enzymes on applesauce, help count out enzymes and pills, squirt hypertonic saline into nebulizer cups.
- Teach basic words for CF care. Slang is okay for now; we used "breathers" and "thumpers" until our kids were in elementary school.
- Help your child learn to label basic emotions like: happy, sad, mad, and scared.
- Help your child learn the words to describe what his or her body feels like: "My tummy hurts", "It hurts here", "I am hungry", "I am tired", etc.
- Engage your child in play activities around CF care and the body: playing doctor with dolls and stuffed animals, drawing pictures, using clay and creating artwork, making up silly songs about CF care, etc.
- Use the magical thinking to encourage a positive attitude towards treatments: put a cape on the vest to encourage being a "Mucus Fighter", make up stories about the magical powers of the treatments/medications, etc.

As you teach your preschooler about the body and CF, remember that each child is different in ability and pace of development. The key is to be patient, friendly, fun and positive. Your young child will take your lead about how he sees himself, the world and CF.

*The segment on the Preschool Thinker is from *Teach Your Child About Hemophilia* by Lauren Kelley.

AVOIDING FOOD FIGHTS:

Tools and Tips for Avoiding and Motivating Picky Eaters

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



One of the earliest power struggles for every parent is around food. Being picky about food is a typical toddler behavior. And when a child has CF, it's an even bigger battle because the stakes are so high. Having a good parenting tool kit around dealing with food issues is essential. There are definitely things that we should, and shouldn't, be doing when faced with a food standoff.

The bottom line is that we can't make a kid eat! Of course we try to. But a basic rule of human nature- especially for toddlers (and teenagers!)- is that when one demands, the other resists. So the more you try to make your child eat certain foods or a certain amount, the more your child will naturally resist.

Kids love emotion so the key is to show lots of emotion when they do things right and very little emotion when they don't. It's easy to do the opposite. We don't even notice when our kids do things right and then we show all kinds of emotion when they goof up! So we have to be thoughtful and clever about how we motivate our kids to eat and one way is with choices. The earlier you start with sharing control around food choices, the better. Here's how it works:

Parent: "It's time for breakfast! Do you want pancakes or waffles?" Kid: "Waffles." Parent: "Great! Would you like one or two?" "Two." "Okay. Do you want maple syrup or strawberry?" "Maple." Good! Do you feel like having bacon or sausage?" "Apples or bananas?" "White milk or chocolate milk? You get the idea..."

By using choices, kids of all ages are more likely to actually eat well because they are involved in the decisions. Here are some more tips for avoiding food fights that I've picked up over the years:

- Do not show anger and frustration over food issues.
- Use dessert and treats as a positive consequence for eating properly. Our kids are not allowed to drink soda pop or eat junk food unless they eat their regular meal first.
- Regularly involve your kids in the food planning and preparation. When they help you plan and cook the meals, they are a lot more excited about eating it!
- Use the power of example. *You* be excited about trying new foods and eating properly. Say things out loud like "I feel so good when I take good care of my body with good food!" or "I've never had this food before but I really like it!"
- Be aware that your child will be teething which can affect appetite. During teething, try serving softer foods and cold foods like milkshakes and homemade popsicles.
- One mom shared how she gets her 4 and 7 year olds with CF to try new foods. They don't have to eat it, just take a tiny taste. And she sneaks special toys into her CF clinic visits so when her kids report on all of the new foods they tried, the doctor gives lots of praise and the special treats.
- Another mom shared about "No thank you bites." Once her children take a little taste, they can say, "No thank you." And, this smart mom makes sure she always has at least two other items on the plate that her children like.
- When grocery shopping, let your little ones pick out some food items they want to try.
- Kids commonly take about five or six tries of seeing a new food on their plate before they accept it. Parents generally give up on the new food way before then.

- Kids tend to like “pure” foods rather than mixtures. So for example, they are more likely to eat meat, potatoes and a vegetable rather than a casserole that mixes the three. I’m honestly not sure why. But a lot of kids don’t like their foods to “touch” either. Go figure...
- Children taste foods differently than adults; some flavors are stronger and others more bland. If something tastes good to you it doesn’t necessarily mean it will to your child. Also, kids are very sensitive to texture.
- Presentation matters. Gourmet chefs at expensive restaurants know the secret to appetizing food: Make it look good on the plate!
- Be creative and fun! Make food in fun shapes or colors. Even my older kids still like Mickey Mouse shaped pancakes. Make the food look like a funny face on the plate. And sometimes just adding a new flavor will help like nutella, peanut butter, ranch dressing, or ketchup.
- Don’t become a short order cook. Cook one meal for the family but stay flexible. For example: With spaghetti, my son likes sauce and my daughter doesn’t. So I serve the sauce on the side as well as butter and cheese for my daughter. Then they can make their plate how they like it. Don’t pre-mix in salad dressings. Let them pick. Choices, choices, choices.
- Make positive comments about good things that might happen after meals are eaten: “I sure hope we finish up all of our dinner so we have enough energy to go to the park!”
- How do you tell if it’s the child who has the problem or the parent? Generally speaking, if your child eats pretty well for other people like Grandma, your spouse or partner, or at preschool but continually battles you at home, then it’s likely that your child has figured out that food is your hot button and isn’t hesitating to push it! Ineffective parenting responses can turn a typical toddler stage into a perpetual battle. Showing anger and frustration is the top one.

Lori J. Stark, PhD, a Professor of Pediatrics at the University of Cincinnati College of Medicine has done some great research on motivating kids to eat and here are a few of her suggestions:

- Limit mealtime to about twenty minutes. Dr. Stark says that this because there is a biological response that all humans have in which the stomach tells the brain it is full after 20 minutes of eating. Therefore little eating is likely to occur after 20 minutes.
- So she says to focus on helping your child get as much food as possible within the first 20 minutes by paying attention to behaviors that support eating such as loading food on a fork, taking bite after bite, chewing quickly, swallowing quickly, trying foods, and finishing foods. Give compliments and praise; be enthusiastic and specific: “Kate, I love how you took three big bites of your hamburger!”; “Sam, smart idea to load your fork while you are chewing that bite.”
- She also tells us to ignore the behaviors that interfere with eating, like dawdling, chewing excessively, talking excessively, complaining about food, and complaints about not being hungry. So be picky about where you give your attention and do not give it when the child is not eating. The trick is, that as soon as the child starts to eat or even picks up their fork, you need to compliment this behavior.

Here’s an important final point about kids who don’t want to eat: Be sure to rule out medically-based reasons before just assuming that it’s a behavioral problem. Resistance to eating can be caused by many things including acid reflux, sinus or lung infections, pancreatic insufficiency, food allergies, or medications which might cause stomach upset or decreased appetite.

Be sure to discuss food challenges with your CF team. Your nutritionist, dietician, child life specialist, or psychologist can help you foster healthy eating habits. The good news about using effective parenting strategies at mealtime is that you, and your CF Team, will be more quickly able to figure out if the problem is a medical issue versus a behavioral issue and respond accordingly.

Bon appétit!

ADVICE FROM OTHER PARENTS

Insight and Encouragement From Parents Who Have Been There

Other parents of children with CF can help you put together the pieces of the CF puzzle. They are always willing to share tips and tricks, so you can master all that comes along with this stage - especially the challenges that come with caring for your child's CF. Here are some experiences, tips and encouraging words from other CF parents on how they handled their Picky Eaters and Chest Physical Therapy:

Picky Eaters

As mentioned in earlier pages, toddlers, by nature, can be picky eaters. Mealtime can become a stressor around the house, but with a little patience and good parenting skills, picky eaters can outgrow this stage. Here are a few pointers from other CF parents:

One thing I had to learn was that being a picky eater is part of what it means to be a toddler and has very little to do with CF. It can be more stressful to CF parents because of the importance of calorie consumption, but it's just part of being a toddler. - *Ryan, dad of 3 year old with CF*

Even if your child is a picky eater, don't shy away from having them try new things. My daughter is a very picky eater, but I'm often surprised by what she'll eat. Not to mention her tastes are changing all the time, one day she loves something; the next, she'll turn her nose up at it. - *Cynthia, mom of 3.5 year old with CF*

We battled over food and my son was getting to a dangerously low weight. We finally got a G-Tube and it was the best decision for us. Since he gets fed at night, we don't feel so pressured to make him eat. And guess what? Now he eats his food! Plus with his night feeds, he is gaining weight very quickly. - *Jed, dad of 4 year old with CF*

My son is a better eater when he's part of the process. At the store, he gets to put the produce into the bags. He helps me garden and picks the veggies when they're ripe. Before I start dinner prep, he chooses between two different side dishes. - *Mary, mom of 3 year old with CF*

If I'm about to feed my son something I think he may not be too into, I call it by a fun name: kiwi wheels, banana boats, broccoli trees, mashed potato clouds. We'll sometimes come up with the names together. I'll ask, "What do you think this looks like?" and we'll go with what he says. - *Cynthia, mom of 4 year old with CF*

Chest Physical Therapy

Chest Physical Therapy, CPT for short, is often started in infancy. Most start with manual CPT, a steady "thumping" of the hands on the chest, back and sides. Often toddlers start using a mechanical vest system, a machine which uses air pressure to vibrate a vest worn by the child. Here are some tips from parents on how they make treatments fun and how they successfully switched from manual CPT to the vest.

Treatment time is the only time of the day that we allow our son to watch television. For him, it seems like a reward to do his treatments. We put on his favorite show or pop in his favorite movie. It helps him sit still and keeps him distracted while getting his treatment. - *Kate, mom of 2.5 year old with CF*

At first the vest can be overwhelming; it's unfamiliar and loud. There may be some tears, but stick with it. Introduce the vest for short periods and make sure you're always excited, positive and reassuring. Eventually, they will get used to it! - *Claire, mom of 3 year old with CF*

My daughter was uneasy when we first started the vest. We made it fun and kept her distracted by encouraging her to talk and make noises to hear how the vibration affected her voice. This always makes her laugh and the vest has become a "toy" not a machine. - *Allison, mom of 3 year old with CF*

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 information, 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.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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