

THE ELEMENTARY SCHOOL YEARS

a parent's guide to healthy living with cystic fibrosis

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AGES AND STAGES: CF AND THE ELEMENTARY YEARS

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®



The grade school years can be the golden years of parenting. Kids this age are open to life and learning. Like little sponges, they soak it all up. They can be easy to teach and fun to be with. Say “Goodbye” to Candy Land and “Hello” to Monopoly!

Raising kids this age can seem simple. Their desire to please adults shows in the way they behave. Despite power struggles and issues with schoolwork, food choices, and medical treatments, kids can be made to do what adults want them to do.

To bribe, nag, yell, threaten, remind, punish, or lecture may work, but only with young kids. When kids become teens, the same approach may cause more problems than it fixes such as rebellion and bad attitudes.

Decades of research shows that the approach parents use affects how kids “turn out” as teenagers and adults. Diana Baumrind’s landmark 1960s research is used in much of what is written today. Dr. Baumrind described three parenting styles: Authoritarian, Permissive, and Authoritative (Baumrind, 1966). Research shows that the Authoritarian and Permissive styles can cause behavioral, social, physical, and mental health issues. Authoritarian parents are strict, demand much, and are not open to the child’s point of view. Permissive parents rarely discipline, “give in” to the child, and don’t set limits well.

So that’s what *doesn’t* work. The good news is that, by being aware and using some simple tools, parents can change their style to one that works for most kids of any age.

Research shows that *Authoritative* parents more often have happy, capable, successful kids (Maccoby, 1992). We ALL want this for our kids! So what *is* an Authoritative style? Love and Logic®, a well-known parenting program, calls this style a *Consultant Parent*. Consultant Parents are clear about limits and what they expect yet respond with warmth and are willing to listen and discuss. When kids fail to do what is expected, these parents focus on problem solving and teaching. They are calm, nurturing, and apply consequences rather than being angry and punishing.

The goal: be a Consultant Parent. This is vital for kids with CF. Each family is different, so how you use this parenting style depends on how you were raised, your culture, values, and personality. Here are some tips:

1. *Use choices to set limits instead of telling a child what to do and when to do it.*

Kids need limits and some control over their lives and bodies. Don't give kids with CF the choice of whether or not to do their treatments. Do give them some choices about how, when, and where. There will be fewer power struggles the more you share control.

2. *Replace statements with questions.* Jim Fay, co-founder of Love and Logic®, says that we need to make sure that our kids are doing their fair share of the thinking. If we don't, we get pulled into working harder on their lives than they are. How can we help them prepare for a world full of decisions and consequences? Replace statements with questions:

- “When will you be doing your CPT today?” instead of “Do your CPT now.”
- “What else can you eat today to get enough calories?” instead of “Eat all of your food.”
- “What might happen to your lungs if you forget to do your breathing treatments?” instead of “Don't forget your breathing treatments.”
- “What is the best choice for your body?” instead of commands.

3. *Learn how to talk about hard things.* It is hard for parents to discuss issues like life-expectancy with kids. We have written much on the subject elsewhere. Here are some highlights:

Tough news should be shared in a loving, matter-of-fact way. Be truthful, gentle, and hopeful. Kids take their cues from parents. If parents don't show fear and worry, often their kids won't be afraid and worried. If you don't know how to handle these issues with your kids, ask questions. Your kids may end up guiding you! Some examples of questions:

- “What do you know about CF?”
- “How are you handling it?”
- “What can I do to make things easier for you?”
- “Do you have any questions about CF?”

Prepare ahead of time. Kids pick crazy times to ask questions like “What is sex?” or “Will I die from CF?” Be ready!

4. *Teach kids early about their medical conditions.* Be clear about the results of non-adherence. It is vital for kids to learn the facts about how CF affects them and what they must do as a result. Seek out resources designed for your child's age. Be honest! For kids to make good choices, they must know the potential results of bad choices. Show curiosity, rather than frustration, when talking about non-adherence. Ask questions like:

- “What might happen if you miss treatments?”
- “How will your body fight infections if your weight is down?”
- “What is your plan for staying out of the hospital this month?”

5. *Fully use teaching moments.* In our busy lives, we forget to use everyday moments to teach our kids. Besides talking about the big issues, “think out loud” with your kids daily about what is going on in their bodies, why things are happening, and what choices are being made.

6. *Wise parents show their love by helping their kids take charge of their own health.* Start young! Give options and allow kids to make their own small choices early on. They will grow to be more responsible every day.

7. *Be sad, not mad, when your child makes poor choices.* As kids become more responsible, mistakes happen. Prepare for them! Kids are human. They will forget to take their medicine. The way parents respond affects what kids learn from their mistakes. Respond with empathy or sadness *before* you impose consequences. Empathy and consequences keeps kids close *and* causes them to think and learn from mistakes. Anger and punishment causes a fight or flight response.

8. *Allow your kids to bear the brunt of their mistakes when the price tag is small.* Wise parents raise kids who “get” that their actions have results that affect the quality of their lives. Instead of trying to prevent or fix mistakes, allow kids to deal with the results of their choices (as long as their choices don’t result in serious harm). There’s no better teacher than the school of hard knocks. Start early, while the price tag for mistakes is much lower.

9. *Focus on the positive. Catch your children when they do things right more often than when they don’t.* Encourage them with positive responses like “Wow! How did you remember to take your enzymes all by yourself?” or “I’ll bet you’re really proud of yourself for eating all of your lunch!” or “I noticed you took your pills without my reminder. Way to go!”

10. *Set a good example.* Take good care of yourself. Take responsibility for meeting your physical, mental, and emotional needs. When we take good care of ourselves, our kids learn from our example and are more likely to take good care of themselves, too.

So that’s how we increase the odds of raising children who are responsible, confident, independent, and successful in *all* areas of life (even self-care). The grade school years are where the countdown to adulthood begins.

From the award-winning book “Parenting Children with Health Issues” by Foster W. Cline M.D, child psychiatrist and co-founder of Love and Logic®, and Lisa C. Greene, mom of two kids with cystic fibrosis and parent educator. www.ParentingChildrenWithHealthIssues.com.



CYSTIC FIBROSIS AND SCHOOL

By Lisa C. Greene

CF and school can be stressful. Kids with CF can have a long list of special needs that teachers need to know about including...

- being allowed to go to the bathroom any time,
- having water and snacks readily available,
- getting medicines at school,
- staying away from sick students,
- making up missed schoolwork,
- fielding questions about CF, and
- dealing with CF-related teasing.

The way parents and teachers handle these needs has a big impact on how kids with CF see themselves. Here are some guidelines to empower your child at school:

1. *When your child starts school, be open about CF.* Be honest and matter-of-fact about your child having CF. Don't keep it secret. Secrets leave voids. Kids fill voids with stories and half-truths, especially if a child is getting "special treatment". I have found that when I am open and do a classroom training session, the students are more apt to support and less apt to tease. Talk with the teacher. Share your concerns. Problem-solve together.

2. *From about second grade and up, kids should be very involved in deciding how they want to handle sharing about their CF.* Some decide to keep it private. This is fine, but kids need coaching by parents as they carefully weigh the pros and cons of secrecy versus openness. Keep in mind that at some point, if your child is hospitalized, the news will be out. Secrecy makes this harder. In general, openness and gaining support from others is the best road to take.

3. *Teach ALL of your kids how to share CF facts.* Teach them the words to say. Practice at home. For instance, kids may ask your child why he or she takes pills at lunch. Teach your child to say something like "because it helps my stomach digest my food" instead of "because I have CF."

4. *Make sure that teachers and school administrators are well informed of your child's needs.* Face-to-face meetings and written documentation are essential. IEP and 504 Plans are federal regulations put in place to guarantee an education for children with special needs (which includes medical issues). Check with your social worker for help with this.

5. *Learn to solve problems and resolve conflict.* Most of us aren't born with these vital skills. When there is an issue at school, help to resolve it. Be a part of the solution rather than a part of the problem. Your child's school life will be harder if you can't work as a team with teachers and school personnel. Never contact the school when you are angry. Wait to cool down and then make a plan about how to address the problem. Stay calm, stick to the facts, and show respect while searching for common ground. Parents and teachers need to be partners with a goal of doing what is best for the child. This applies to your child's medical team as well.

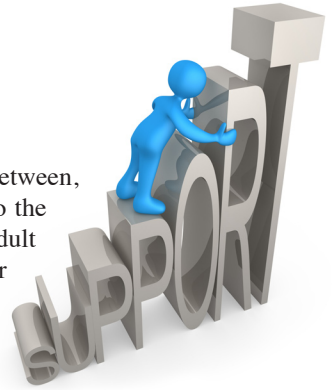
Following these simple, practical tips will help ensure that your child has a great school experience over the years to come.

Lisa C. Greene is the mom of two kids with CF, an author, public speaker, and family life educator. For more "CF and School" tips, including a sample 504 Plan for CF, visit www.TipsForCFParents.com.

SUCCESSFUL TRANSITIONS

Start Early, Step by Step

By Lisa C. Greene and Kecia Nelson, MSW, LCSW



Whether your child is a toddler, a teen, or somewhere in between, transition is a word you need to know. “Transition” refers to the process of getting kids (and parents) ready to shift into adult health care. It can take years to get kids ready to manage their own health care. The more complex their health needs, the longer it takes.

Transition should be a step-by-step process that should start before kids are school aged. Have you seen the milestone charts that doctors provide at well-baby visits? Kids reach milestones in how they play, learn, speak, act, and move.

For kids with CF, there are also milestones in learning the skills needed to care for themselves. A transition plan will help make sure this happens. This is a written plan that gives goals and guidelines for the right tasks at the right time so that kids become prepared, able young adults.

Some of these plans are simple checklists. Others include surveys, tests, and goal-setting help. Check with your CF clinic about a written plan. If they don’t have one, there are samples at www.TipsForCFParents.com under “Transition Plans”.

So that’s what “transition” is, but why does it matter? Research shows that adverse health outcomes including mortality can occur with a poor transition plan. (Kennedy et al, 2007). Transition is a vital issue that can change lives!

Some health care providers advise that the formal transition process start in the pre-teen years. Experts in child development, though, advise that a tailored plan start much younger.

One of the most common ways parents mismanage transition is by doing too much for their kids past the early childhood years. Then, in the teen years, when parents and doctors want kids to manage more of their care, kids are not prepared. Many resist getting “dumped on” and all are set up to fail. (Kieckhefer & Trahms, 2000)

Instead of falling into this trap, wise parents expect their kids to manage their own health care in small but growing ways during the school age years. By about ages 11 to 12, most children with CF should be able to:

- take enzymes independently.
- manage their airway clearance.
- be well on their way to independence with breathing treatments including cleaning and storing their supplies.
- answer many of the questions from health care providers on their own.
- raise issues or concerns with parents and/or health care providers.

- use the proper names for medicines and explain their use.
- initiate exercise and sports including watching salt and fluid intake.
- help spot changes in their respiratory baseline and continue learning about how to treat exacerbations.
- help spot changes in their GI baseline and continue learning about how to treat malabsorption.
- understand lab tests (blood, sputum, x-rays, PFTs, diabetes screening, etc.).
- know basic CF nutrition and the importance to lung health.
- be well on the way to making good food choices independently.
- explain CF to friends and respond to their comments in productive, healthy ways.
- grasp basic genetics and why some people have CF and others do not.
- maintain a health care notebook, keeping notes for clinic visits.

Life is easier for parents when they oversee the work instead of doing it all. Kids also benefit in many ways. They learn about good CF care, feel empowered, confident, and develop an attitude of “I can do it!”

Transitioning your child can feel like a large mountain to climb. However, there are many other parents of children with CF who are currently navigating the same journey, and others who have finished successfully. Here are some tips from other parents:

It’s important to let kids know that you will be there to help them, but that they need to help themselves, as well. You cannot do everything for your child, all of the time, at any age. – *Mom of 25 year old with cystic fibrosis*

Don’t think about the end goal. Instead, just focus on the day to day. I get overwhelmed when I try to think about handing over all responsibility to my child, so I think of it in pieces. For example, this month we are tackling her setting up her treatments. We will worry about another aspect of her care next month. - *Mom of 7 year old with cystic fibrosis*

We have to slowly teach our children how to live independently in a lot of areas of life: decision making, finances, household management, you name it. Our job as parents is to teach our children how to be fully and solely responsible for themselves by the time they’re an adult. Transitioning their CF care is no different! – *Mom of 32 year old with cystic fibrosis.*

References:

Kennedy A, Sloman F, Douglass JA, & Sawyer SM. (2007). Young people with chronic illness: the approach to transition. *Internal Medicine Journal*, 37: 555–560.

Kieckhefer, G.M.& Trahms, C. (2000). Supporting development of children with chronic conditions: From compliance toward shared management. *Pediatric Nursing*, 26, 4, 354-363.

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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 children starting school:

Help you child's school understand CF - We worked really hard to help the school staff understand CF. We met with the teachers before our daughter started school to explain CF and daily care. Additionally we gave them a document that summarized the key points, so they could have something to take with them. Lastly, we set up a meeting with the teachers and our CF team, so that they could get all of their questions answered. - *Gemma, mom of 6 year old with CF*

Set up a formal plan - We have a 504 Plan set up for our daughter, to ensure she gets the care she needs while at school. The plan outlines the accommodations that will be made for her while she's at school. Each teacher she has - including art, health, and physical education - gets a copy. - *Katie, mom of 9 year old with CF*

Get into a steady routine - When your child starts school, it makes your schedule a little less flexible. However, we've found that getting into the steady routine makes it easy to fit treatments, school, and extracurricular activities. We do a treatment first thing in the morning while we watch TV, after school - if she's sick and needs an extra treatment - and one before bed. - *Tammy, mom of 9 year old with CF*

Learn your school's policies regarding digestive enzymes - The biggest hurdle that we had with school was figuring out when and how our daughter could take her enzymes before lunch. Every school and every state has different rules. Some allow kids to carry the enzymes with them, others require them to be kept as the nurses office, some keep them at the teacher's desk. Find out what your school's rules are. Then work with your school, and your child, to figure out the best system for your child. - *Terri, mom of 22 year old with CF*

Special arrangements shouldn't become special treatment - It's important to remember that not everyone knows what CF is. It is our job as parents to educate school staff about CF, but at the same time, encourage them to treat our children like their peers. Occasionally, our son may need different arrangements, but he's a second-grader first. - *Trisha, mom of 8 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 facts, comfort and friendship. Be sure to check out any medical advice with your doctors *before* putting it into practice.

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.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.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.

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