

HELPING SIBLINGS COPE

a parent's guide to healthy living with cystic fibrosis

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CF SIBLINGS HAVE SPECIAL NEEDS, TOO!

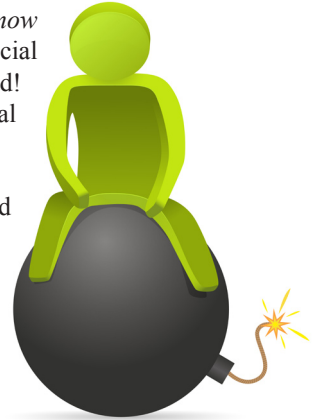
What Siblings Want You to Know

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

“Help! We will have a house full of guests for a party. I *know* what will happen. People will favor my daughter with special needs and almost ignore her sister. It makes me so mad! What should I do?” – Dad of a child with a developmental disorder

“My five-year-old son had to go to the hospital and I stayed with him. His big sister was so mad at me for leaving that she wouldn’t look at me when she came to visit. How can I help her?” – Mom of a child with cystic fibrosis

Kids with cystic fibrosis (CF) face many tough issues, *as do their siblings*. It is not easy for busy parents to nurture the sibling bond, care for their child with CF, and take care of themselves, too. Here are some practical ways that parents can help siblings cope:



1. All kids in the family need some one-on-one time with parents. Parents may need to tag-team or get help from friends and other family members. Even a quick fast-food meal can be a special time to connect.
2. Turn off the electronics when you are together as a family. Focus on each other, not the screen. Play games, exercise together, enjoy the outdoors, and have fun as a family. This is what your children will remember when they are older.
3. Do chores together. Chores are a vital way for *all* kids to invest in the family, feel a sense of belonging, learn skills and develop responsibility. Keep expectations reasonable and pay children for “extra” services. Show that you are thankful for the help.
4. Set written schedules and use a family calendar. Kids thrive on structure and routine. This also helps them start to learn about managing time and priorities.
5. When children show upset feelings, *listen with acceptance, not approval*. We all need time to vent and want our feelings accepted. This does not mean that you agree with the content of the complaint. Kids feel accepted and heard when parents listen to and reflect their feelings. Empathy can absorb negative feelings.

Words that reflect feelings:

“You seem upset about something. Do you want to talk about it?”

“You sound like you are sad about this. Do you need a hug?”

Words that show acceptance (not approval):

“Thanks for letting me know how you feel.”

“I can understand that you would feel that way.”

6. To help kids move to a solution, listen and then ask questions:
“How long do you think you’ll be upset about...?”
“What is your plan for handling...?”
“Do you have any ideas about how I can help that will work for us both?”
7. Children with CF need extra physical contact from parents. Siblings notice! Make sure you also give the healthy child plenty of touches, hugs, and eye contact. “Ok, Jack, it’s your turn! Lay down where Jill was and I’ll give you a back rub.”
8. Be sure all children in the family, including siblings, get correct information about CF. Kids tend to fill gaps in their knowledge with wrong information. Well-siblings might even blame themselves for giving their sibling CF.
9. Teach relatives, school staff, and others about the needs of the healthy sibling. Discuss this with siblings first, especially older ones. Make a plan together for handling friends and relatives at social events. This will reduce stress and hard feelings.
10. Get to know your children and their unique needs. Read a book on personality styles or love languages. The more you know about your children’s needs, the better able you will be to respond in a way that works when problems arise.

As you journey through life with a child with CF, keep these tips in mind:

1. *Don’t let feelings of guilt affect how you respond to your children.* Without knowing it, parents can validate feelings that hurt rather than help. Here is one way this can happen:

Parents often feel guilty about the extra time and energy they spend on their child with CF. The healthy sibling picks up on this and plays the blame-game: “You never spend time with *me!*” And when the child blames, guilty parents tend to apologize: “We’re sorry, Jack, but Jill needs a lot of our time right now.” Then Jack responds with: “That’s not fair! You should spend more time with me!” This leads to more apologies and maybe even fights. And it becomes all too easy for the well-sibling to feel like a victim: “If it weren’t for Jill’s CF, I’d be happy.”

Instead of getting caught up in the guilt and blame game, try this: With love, empathy, and a big hug, say, “Jack, you sound frustrated. It is hard right now. Thank you for understanding that Jill needs more time while she is in the hospital. Not every kid could handle this so well.”

2. *Common mistakes parents make when facing an upset child:* (1) They validate the upset feelings by giving too much sympathy (2) They apologize unnecessarily (3) They become defensive and argue (4) They invalidate the feelings by dismissing the child’s concerns: “Jack, just man up!” So instead, respond as shown above with empathy, accepting the child’s feelings, not giving approval to “acting out”, offering an “I believe in you, you can cope” message, and moving into problem-solving: “Jack, I can’t take

you to the park today but let's make a plan to go on Saturday.”

3. *Siblings of kids with CF are kids first.* Before “blaming” CF for sibling problems, see if there are non-CF reasons for family issues. Maybe your healthy son is grumpy and upset because he is having a problem at school or with friends. Look at the whole child before you assume that CF is the cause.

4. *Parents model problem solving, conflict resolution, and coping skills.* Kids are like copy machines. They learn how to cope with CF by watching how parents handle stress, resolve conflict, and solve problems. Setting a good example will help your kids learn how to cope well with CF and life.

5. To be a good model for kids and avoid burnout, *parents must care of themselves.* Take time for date nights and self-care. Eat right. Exercise. Have some fun. Do not allow disrespect from the kids (or each other). Learn to say no to the many demands that others try to put on your time and energy.

6. *Focus on positive things.* Foster a spirit of helping, teamwork, and being thankful. As a family, count your blessings each day: work, home, food, health care, freedom, friends, family, love, faith, hope.

7. *Learn good parenting skills.* To do a good job, you need good tools in your toolbox. Learn how to defuse a fight, set limits without causing power struggles, solve problems together, and talk about tough stuff.

8. *Don't let CF define you, your child, or family.* CF is only a part of each of you. Your family and each member are unique, with special hopes, dreams, fears, needs, and gifts.

9. *Stay balanced.* If you feel guilty about spending less time with siblings, do not try to “make up for it” by buying things and not setting limits. This causes more problems than it solves. When spoiled kids do not get what they think they are entitled to, they blame others, get angry, and grow bitter. This can destroy people, friends, and families.

A parent's influence, both good and bad, can last a lifetime. Nurture your bond with your children and their bonds with each other. Your legacy will be kids who nurture others and impact people for good... just like you!

From the book “Parenting Children with Health Issues: Essential Tools, Tips and Tactics for Raising Kids with Chronic Illness, Medical Conditions and Other Special Needs” by Foster Cline, M.D and Lisa C. Greene available online and in bookstores. Dr. Cline is a well-known child psychiatrist, author, and co-founder of the popular Love and Logic parenting program. Lisa is the mother of two children with Cystic Fibrosis and a parent educator. For free audio, video, written resources, visit <http://www.ParentingChildrenWithHealthIssues.com>.

SIBLINGS: “WHAT ABOUT ME?”

By Breck Gamel

I went to a great workshop on siblings. The speakers were Heather Bensman, PsyD and Vicki Kelley, MS, CCLS. It was based on the book “Sibshops: Workshops for Siblings of Children with Special Needs” by Meyer & Vadasy.

The subject of siblings spoke to me. My son struggles with the fact that his little brother has CF. The workshop opened with the speakers listing some of the many feelings that siblings of those with CF often have: guilt (for not being sick), loss/loneliness (for being overlooked, since they’re not sick), anger/resentment (over getting less attention), stress (because their sibling is sick) and shame (because their family/sibling is different).

A highlight of the workshop was hearing about the positive aspects of being the sibling of a child with CF. I will keep this list close to my heart as I do my best to parent a sibling of a child with special needs. Here’s some of what’s on that list:

- **Mature** - Siblings mature faster. They face major life and death issues before their peers do.
- **Loyal** – CF siblings are often very loyal to each other. They protect and help each other.
- **Insight** – CF siblings often have real insight into what really matters in life, like the need for close ties with family and friends. They know first-hand the value of support from others.
- **Empathy** – Kids learn empathy and how to care for others when they see the issues their ill siblings face.
- **Advocate** – By being in CF Walks and raising money for a cure, siblings of those with CF often learn how to stand up and speak for others.
- **Vocation** – Siblings of those with CF are exposed to more careers. They see the need for doctors, researchers, nurses, child life therapists, etc. These folks have had a strong impact on their family.
- **Tolerant** – Siblings learn quickly that we are all special and unique. They see it lived out in their families.
- **Competent** – Siblings of those with CF face their own issues. They don’t get as much attention as their ill siblings. Still, they need to be seen and known. This is a chance to learn creative problem solving. It’s a chance to build a positive self-concept and social competence through their own unique skills.

As a parent, I love the concept of using our “CF journey” to support both of my kids. The speakers said that the time to use their CF journey to encourage kids is NOT when they or their siblings are upset. The right time is when they are feeling good about themselves (like for making the team or getting a good grade). It’s at that point that you can say, “You know, I bet all of those blood draws you’ve dealt with have helped you to ...(whatever the child is proud of)” or “I wonder if all of that extra responsibility you’ve had with taking your medicine has helped you prepare to...(whatever the child is proud of).”

I am so glad for this positive approach! It’s helped me to encourage, empower, and inspire both of my kids as we all learn to live with CF.

Breck Gamel is the mom of three kids, one with CF. You can read more about her family at her blog: <http://bennettgamel.blogspot.com>.

SIBLINGS AND CF: TOOLS FOR EMPOWERMENT

By Kirsten Black, Marmie Fishel and Lisa C. Greene

Well siblings, just like kids with CF, need emotional support and education about CF. All family members have a life-long, ever-changing need to learn about CF, CF-care, and what the future may hold. Just as you teach kids about getting dressed and brushing teeth, teach them about how CF affects the body and how treatments help. Use books, games, pictures, dolls, and stuffed animals. Use real and toy health care equipment. Take time to play. Ask open-ended questions to learn what each child knows and thinks about CF.

When you can, let siblings be a part of CF clinic visits. If your child with CF must go to the hospital, ask the staff for a sibling tour and things to do that include siblings in the process. Child life staff can give insight into how best to teach siblings about CF.

At school, talk to the well sibling's teachers and school counselor. Often, kids are scared to share their worries with parents and close family members; they don't want to add to the stress. Find supportive adults who play a big part in the child's life but are not involved first-hand and teach them about CF. This broadens the child's support system.

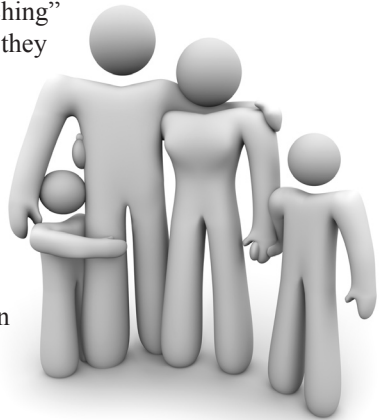
Well- siblings have many feelings about how CF affects their brother or sister. Parents can help them deal with these feelings by creating a loving, open, honest environment. Be aware of how children learn and cope throughout their different stages of development.

Preschool Children

Young kids often struggle with how to share their feelings. Provide activities that help them understand and deal with feelings. Use simple words to describe feelings like happy, sad, mad, and scared. Young kids sometimes think that their "bad" thoughts, feelings, or wishes about their sick sibling caused bad things to happen. Let them know that this is not the case. Kids may worry about "catching" CF from their sick sibling. Teach them the facts so they know the truth.

School-Age Children

Feelings of guilt are common in school-age kids. They need to know they are not to blame. Kids this age are very aware of differences. You may notice your child working hard to "earn" your love and praise or acting badly to get your attention. Children this age also may worry about how the sibling with CF might affect them at school with peers.



Teenagers

Teens begin to fully understand the realities of CF. They may express concern over their sibling's future. They may also be worried about how having a sibling with CF will affect their own future. Teens may resent the extra work that comes with caring for a sibling's health needs if they are over-burdened.

Here are some ways that you can help your well child or children:

- Don't forget the needs of well infants and toddlers. They will often sense stress in others and get upset. Having a routine and the same people caring for them can help.
- Host a teddy bear clinic/tune-up. Let your kids (with and without CF) play doctor with a teddy bear or doll. Pretend the "patient" has CF. Let them direct what is done and said. They may end up revealing errors in their thinking or worries about CF. You can say what's needed to clear errors and calm fears, but keep it brief. Don't stop the play.
- Make a Worry Box. Give kids and teens a safe way to "unload". Have them write down their worries or fears, especially when it comes to a sibling with CF. Put them in the Worry Box. Make a regular date to address every issue in the box and stick to it.
- Many kids feel powerless to help their sibling with CF. But they CAN help. Have them serve others by raising funds for their local CF walk, working with the clinic social worker to "adopt a family" for the holidays, or collecting items for the children's hospital.
- To express themselves, they can draw, paint, sculpt, write stories, or journal.
- Teach them to relax and care for themselves. Have them exercise, eat healthy, listen to music, and pursue hobbies.
- Connect them with other kids dealing with similar issues. Sibshops programs are offered in many hospitals around the world.

Where there is CF, there are questions and concerns. With a little extra effort, kids with CF and kids whose siblings have CF can be given the tools they need to answer questions and deal with concerns.

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:



Explain the differences in nutritional needs - We have five children and our youngest has CF. All four non-CF siblings are envious of our CF child's diet! It's anything goes, anytime of day, anywhere. We try our best to explain *why* their sibling gets to eat differently and why they shouldn't eat the same way. We hope that one day they'll fully understand. – *Jen, mom of 3 year old with CF, 4 children without CF.*

Make time for non-CF child(ren) - Make sure to take extra time out to spend with your non-CF child to make them feel special. I often schedule a "chick day" with my daughter, where we just spend part of the day doing something special together. – *Jodi, mom of 9 year old with CF, 6 year old without CF.*

Help your kids work through their feelings - We have two children with CF and one child without. Whenever one of my children with CF is sick, my child without CF goes through feelings of guilt. We talk to her about her feelings and help her work through it. – *Suzanne, mom of 11 and 7 year olds with CF, 9 year old without CF.*

Create a safe environment to share feelings - The biggest piece of advice I can give is to talk everything through with your kids. Sometimes they act out, but there is always a reason why. Make sure you give them a safe environment to share their feelings no matter what they are. It is hard to have CF, but it's also hard to sit by and watch your siblings go through so much. – *Katie, mom of 11 year old with CF, 9 year old without CF.*

Seek professional help when it's needed - My daughter (oldest) doesn't have CF, and my son (the baby) has CF. Our daughter has had a difficult time adjusting to her younger brother and is often jealous of how much attention he gets. She wouldn't talk to her father and I about her feelings, so she saw a therapist for a short time to help her work through her feelings. – *Mindy, mom of 3 year old with CF, 8 year old without CF.*

Bonding over CF - Both of our children have CF. My husband and I find that they share experiences, emotions, and feelings that we will never fully understand. It is incredible to watch them bond over their CF. – *Maggie, mom of 12 and 14 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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