

Growing Up With CF in the Family

Cystic fibrosis (CF) doesn't just affect the person with CF. It can impact the whole family, including siblings. How can you talk with your other children about CF? How will their lives change? And what are the signs that they might not be adjusting well?



Back to basics

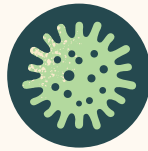
Staying healthy and avoiding germs is not just something for a person with CF to worry about. The whole family can practice good hygiene together.

Put the principles in kid-friendly terms by talking about:



Keep the outside out

Make washing hands a routine upon arriving home.



Keep germs to yourself

Even young children can learn to cough or sneeze into a tissue to help contain infectious droplets.



Keep yourself healthy

Practicing healthy habits, like getting a yearly flu shot, benefits everyone, not just those who are more prone to infections.

Talk about the realities of CF

For many children, a sibling with CF could be the most personal experience they have with a serious illness, especially in someone close to their age. They may be curious about what is going on with their sibling's health and **begin asking questions like:**

Example Dialogue

Did my germs make Leo have to go to the hospital?

Will Maria's CF ever go away?

Why does Lucas have the CF gene and I don't?

These tough questions can be hard to hear as a caregiver, and it's natural to want to shelter your loved ones from difficult conversations. But remember, open and honest communication with siblings can go a long way and may help keep them from seeking answers from alternative sources or jumping to their own conclusions that involve self-blame or other worrisome thoughts. It's important to instill trust by checking in with them often and answering their questions in an age-appropriate, but matter-of-fact, manner.

Depending on the nature of their questions and concerns, you may also encourage siblings to talk to each other about how they're feeling. Or, if they don't feel comfortable with that and you feel you need additional help, discuss sibling support options with the pediatrician or social worker on your loved one's CF care team to ensure the whole family feels confident, informed, and recognized.

Keeping Up With CF Routines

Children thrive on routine and are quick to notice when things are out of the ordinary. By making CF care part of the family routine, siblings can carve out their own role. When those routines are disrupted, take time to explain things and give warning if you can.

Getting involved in care

Finding roles and responsibilities for siblings during treatment time and in other aspects of care can help everyone feel more included. Start with suggestions, then see what they come up with themselves!

Example Dialogue

Mia, you are in charge of giving everyone one squirt of hand sanitizer.

Jack, can you please pick a yogurt for your brother's snack?

Abi, can you help your sister to put her vest on?

I can play video games with Charlie while he does his treatments.

I can practice spelling when Dad gets Oliver's pills ready.

Many hands make light work

Household chores can give everyone a sense of purpose and responsibility in their everyday routines. Even at a young age, it may be helpful to teach your loved ones how to get involved with these important tasks.

- Toddlers and preschoolers can pick up toys, help put away groceries, or tag along with parents or older siblings as they complete their jobs
- Elementary school-aged children can use disinfectant wipes to clean high-touch surfaces like doorknobs, light switches, countertops, and bathroom fixtures
- Older children can help with meal preparation and sweep, vacuum, or mop, particularly with lightweight tools with disposable sheets or pads
- Teens can help with running errands, like picking up cleaning supplies

“**My aunt would have sleepovers with all of my cousins and when I was really little, I wasn't able to sleep over yet...but I'd go over for a few hours, and if that overlapped with my treatment time, my mom would bring my treatment with me. I would do my treatment while me and my cousins were watching a movie and it was never weird. No one ever made fun of me for it or made me feel different for it.**” - Grace, student with CF

For not-so-typical times

When household routines are thrown out the window due to changes in your child with CF's needs, siblings are likely to catch on quite quickly. This is a time to have grace with yourself, and your children. It is natural that siblings will have less of your attention as you focus energy on your loved one with CF. A frank conversation acknowledging your own limitations and the sacrifices they are making can go a long way toward making siblings feel seen.

Making time for fun

Your family routine doesn't have to be all about keeping things clean and scheduling the day around treatments. Encouraging participation in extracurricular sports and clubs, nurturing their individual hobbies, and prioritizing unstructured time with friends tells siblings that it's OK to have fun and do things for themselves.

Dealing With Emotions

Like anyone, siblings of people with CF experience a range of emotions, and sometimes those emotions are big. As a caregiver, you can help children to recognize the emotions they are feeling and coach them to express those feelings in a healthy way. Picture books can be helpful with this. Talking about different emotions when everyone is calm, such as at story time, can help ensure that they are in the right state of mind to learn rather than to react.

Negative emotions that may surface around a sibling with CF may look like:

Examples



Anger

We always have to leave the park early so that Theo can do his treatments. I want to stay and play with my friends!



Jealousy

Why do you always have time to give Ava her special snacks but not me?



Guilt

I get to do so many cool things that Liam doesn't.



Fear

Will I have to go to the hospital like Sofia does?

No one is perfect at expressing their emotions. Caregivers can also look for clues in siblings' behavior to interpret how they might be feeling.

Younger children may:

- Be clingy and attention-seeking with parents or other caregivers
- Act out or have more tantrums
- Exhibit behaviors they have grown out of, like wetting the bed
- Have nightmares or trouble sleeping
- Be hyperactive
- Lose their appetite

Older children or teens may:

- Isolate themselves and become more introverted
- Seem detached or hostile (could be less talkative than usual or talking back more)
- Be irritable or easily overwhelmed
- Have problems at school
- Act impulsively
- Engage in rebellious or risky activities like fights with peers or drinking alcohol*

*These types of changes to your loved one's behavior could also be a reaction to other situations teens and young adults may go through.

Remember that your loved one's CF care team is your best resource. Figuring out the ways you can function as a family is a crucial part of managing life with CF. They may be able to direct you to additional tools and support systems for all members of the family—including siblings.



It's okay if you don't have all the answers! Learn about CF together with free online resources like:

[CFSOURCE.com](https://www.cffsource.com) The science behind CF and how it can progress

[EVERYDAY-CF.com](https://www.everyday-cf.com) Stories and suggestions for living life with CF

[CFF.org](https://www.cff.org) Articles, personal stories, and advocacy from the Cystic Fibrosis Foundation

[CFRI.org](https://www.cfri.org) Educational and personal support from the Cystic Fibrosis Research Institute

