

WHAT ABOUT SIBLINGS?

HELPING MY FAMILY COPE

A GUIDE FOR PARENTS
AND CAREGIVERS

When children are chronically or acutely ill, normal routines may go by the wayside to make room for hospital and doctor's visits. This can impact the child, caregivers, and also brothers and sisters.

When a child is diagnosed with cystic fibrosis or is experiencing acute illness, siblings might feel confused, upset, afraid, numb, or worried. **Siblings will need time to adjust to their brother or sister's medical needs and treatment.** During that time, allowing siblings to ask questions and express thoughts and feelings can be helpful. Many siblings react in very positive ways — with love, care, and support. They often describe feeling glad that they are able to help out at home and support their sibling. However, some may have trouble adjusting to this new situation.

SIBLINGS MAY FEEL:

- They miss their caregiver(s) and their sibling with CF when they are away
- They only partly understand the situation
- They want to help, but are not sure how
- They feel angry, jealous, left out, or guilty and are not sure if those feelings are okay

CAREGIVERS MIGHT SEE:

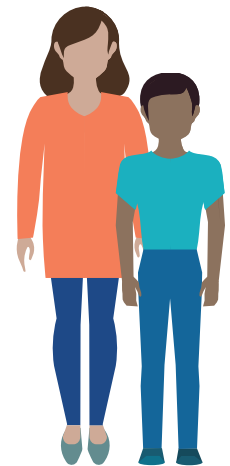


In younger children:

- Clinging to parents or other caregivers
- Having temper tantrums
- Doing things that they had grown out of, like bed wetting
- Having trouble sleeping, having nightmares, or being afraid of the dark

In older children and teens:

- Wanting to be alone or be with caregivers all the time
- Being easily overwhelmed, jumpy, or irritable
- Experiencing changes in behavior, becoming more sensitive or quiet, talking back, or getting into fights
- Having trouble sleeping or having nightmares
- Missing friends or feeling left out
- Having problems in school



If these bother your child a lot or impact daily life, you might seek additional help, especially if problems have lasted more than a few weeks.

10 TIPS FOR HELPING SIBLINGS COPE

- 1. Be patient and give everyone time to adjust.** Members of the same family can have very different reactions and will adjust to the changes in different ways. Talk as a family about how cystic fibrosis affects everyone.
- 2. Keep to everyday routines.** Trying to keep to some everyday routines can help things feel more normal at home. Having regular routines (e.g. mealtimes, bedtimes, chores) and activities give siblings things to expect and look forward to.
- 3. Set limits as usual.** It can be tempting to relax family rules to help siblings feel special or to make up for hard times. However, it is often better to keep most of your family rules and expectations the same.
- 4. Help your other children understand what is happening.** Cystic fibrosis can be confusing and scary for a sibling. Children have active imaginations and they can get the wrong idea about what is happening. Ask questions to figure out what your child knows and give information in clear, age-appropriate ways.
- 5. Encourage your other children to share their feelings.** There are many ways to share feelings (talking, drawing, storytelling, hugging) and different times (dinnertime, bedtime) and places (in the car, at home, in the hospital). Help siblings name their feelings, such as being sad, scared, angry, jealous, or guilty. Share your own feelings and be a good listener, even if what they have to say is hard to hear.
- 6. Spend time with your other children.** It is important to care for your child with cystic fibrosis, but remember that your other children miss you. Try to make plans to spend one-on-one time with your other children. If you are away a lot, call regularly or video chat so you can keep in touch.
- 7. Help siblings feel involved.** Allow them to be a part of their sibling's care. Plan a visit to your local CF care center and introduce them to the healthcare team. Let them choose which toys and games to take to the hospital and make sure you let them know how much you appreciate the extra things they do to help out.
- 8. Help them keep in touch.** If their sibling with cystic fibrosis is away, find ways to help your other children keep in touch. Make cards, write letters, draw pictures, make videos or arrange for video chats, or record a sibling reading a bedtime story. If possible, let them visit their brother or sister in the hospital.
- 9. Encourage siblings to have fun.** Often siblings feel guilty about wanting to have fun. Remind them that it is okay for them to do the things they enjoy, like spending time with friends, hobbies, or extracurricular activities.
- 10. Seek help.** If your other children seem to be struggling, talk to your child's doctor about seeking help from a mental health professional, such as a psychologist or social worker.

TO LEARN MORE

View the CF Foundation and ECFS Guidelines at cff.org/Care-Guidelines/Depression-Anxiety

View the CF Foundation's website on emotional wellness at cff.org/Living-with-CF/Emotional-Wellness

For questions, call **1-800-FIGHT-CF** (800-344-4823) or email info@cff.org.

Adapted with permission from The Center for Pediatric Traumatic Stress at The Children's Hospital of Philadelphia and Nemours/Alfred I du Pont Hospital for Children, a partner in The National Child Traumatic Stress Network. www.healthcaretoolbox.org

