

PARENTING AS AN ADULT WITH CYSTIC FIBROSIS:

UNDERSTANDING CHILD TEMPERAMENT AND DEVELOPMENT

A child's developmental stage and temperament play a role in how they understand and experience the impact of your cystic fibrosis. Temperament is a child's consistent style of reacting and their ability to adjust to their environment. For example, some children are "easy going," some are "easily upset," and some are "difficult to soothe." Some children may need more support to build the skills they need to adapt to changes and challenges. The way a child thinks, feels, and responds is affected by their developmental age and their temperament.

- Identify your child's particular coping strengths and areas of need to strengthen their resilience.
- Provide more support in situations in which your child has had trouble coping in the past.

Children's Ability to Understand Diagnosis, Prognosis, and Treatment

Infants & Toddlers (0-2 years)	Unable to understand, but can sense family stress and changes in routines
Preschoolers (3-5 years)	Limited ability to understand how the present affects the future or logical cause and effect
Elementary School Ages (6-12 years)	Capable of flexible thought and understanding cause and effect
Adolescents & Young Adults (13 years and older)	Able to understand abstract concepts and uncertainty

TIPS FOR STAGES OF DEVELOPMENT: A child's developmental stage is like a lens through which they see the world. Being aware of these stages can help you recognize common reactions to your CF.

INFANTS & TODDLERS (0 to 2 years)

- CF exacerbations are common in parents of infants. Prioritize your health and take time to rest.
 - ♦ Identify adults you can turn to for unexpected needs.
- Everyday interactions while feeding, bathing, reading, or changing diapers can promote attachment through language and touch.
- Infants and toddlers are sensitive to changes in routine, such as being taken care of by a new caregiver.
 - ♦ Keep a book of your child's routines and favorite things. Have your child nap in a portable crib. If they need to sleep at another home, it will be familiar. Although separations can be difficult, babies can thrive even when they have a variety of caring relationships.
- Children under stress may regress to less mature behaviors.
 - ♦ Praise cooperation and self-calming.

PRESCHOOLERS (3 to 5 years)

- Preschoolers are vulnerable to misunderstanding why CF occurs, and may blame themselves (for example, "*I hit mommy and it made her sick.*"). They may think CF is contagious.
 - ♦ You may have to provide repeated explanations of the same topics to help your child learn. Think of how you teach ABCs (over and over again until mastery).
- Preschoolers may incorporate themes of CF into their play.
 - ♦ They may pretend to do a treatment. This is good! Remember to keep your medications out of reach since they may also try to play with or swallow them.
- Preschoolers like to be helpers. Find a way they can help you with your treatments, such as sit with you while you are using your vest.
- Preschoolers often test limits and express frustration at not getting what they want.
 - ♦ Maintain expectations across environments. Remind other caregivers that children thrive when routines and schedules are kept consistent.



ELEMENTARY SCHOOL AGES (6 to 12 years)

- Children at this age benefit from specific information. They are reassured by knowing that parents have a good treatment plan and confidence in that plan.
- School-age children may become preoccupied with the unfairness of illness. They are sensitive to ways that illness may affect their ability to participate in their normal activities.
 - ♦ Respond empathetically to your child's frustrations. *"It is unfair that you had to miss dance class because of mom's appointment. It is okay to feel frustrated."*
- Relationships with individual friends and peer groups become more important.
- Connect with parents of your child's close friends. They can help provide your child additional support during times of need.

"From a young age I knew my mom had CF, but I did not fully comprehend until I got older. When I was young, I just knew she took medication and did breathing treatments to help her breathe better. As I grew older, I gradually learned more and more about what CF is, why she does treatments, and what her medicines do to help her. In high school, I started going to her CF appointments with her to be more involved in learning more, while also supporting her."

– Claudia Hannum, a daughter of a mother with CF

ADOLESCENTS (13 to 18 years)

- Although adolescents may seem to have a mature understanding of CF, their behavior and the thoughts and feelings they express may focus on themselves.
 - ♦ Their understanding may not yet translate into helpful gestures.
 - ♦ Teens may want to spend more of their time with friends and less time with family.
- Adolescents commonly feel frustration, unhappiness, and/or anger when the demands of a parent's illness are at odds with their normal developmental needs.
 - ♦ They may engage in risk-taking behavior to manage distress and seek control and independence.
 - ♦ Balancing warmth with consistent limit setting is important. Seek professional help as needed for assistance with building coping, cooperation, and communication skills.



YOUNG ADULTS (18+ years)

- Parenting is a lifelong endeavor. You remain a key person in your child's life no matter how old they are.
 - ♦ Young adults need the facts about your medical status, including what is known and what is unpredictable. When you share this information, you allow your child to make informed choices that will support their ability to cope and ask questions as needed to get necessary support.

TO LEARN MORE

Visit the CF Foundation's website for information on parenting at:

www.cff.org/Life-With-CF/Transitions/Family-Planning-and-Parenting-With-CF/Parenting-as-an-Adult-With-CF/Planning-Ahead-and-What-to-Expect/

www.cff.org/CF-Community-Blog/Posts/2020/Managing-CF-Parenting-and-Anxiety/

FOR SUPPORT

CF Peer Connect: cff.org/PeerConnect

FOR QUESTIONS

Call **800-FIGHT-CF** (800-344-4823) or email info@cff.org

Adapted with permission from Marjorie E. Korff Parenting At a Challenging Time (PACT) Program, Massachusetts General Hospital www.mghpact.org

Rauch PK, Muriel AC. Raising an Emotionally Healthy Child When a Parent Is Sick (A Harvard Medical School Book). McGraw-Hill Education, 2006.