

PARENTING AS AN ADULT WITH CYSTIC FIBROSIS:

A GUIDE FOR PARENTS
WITH CYSTIC FIBROSIS

TALKING WITH YOUR CHILD ABOUT CF

Parenting well is always challenging, but it is even more complicated when dealing with potentially difficult physical and emotional symptoms of cystic fibrosis and the demands of its care. We hope to give you the knowledge and practical tips to help you talk about CF with the children you love in a way that helps them feel secure. If you are taking the time to learn about these important issues, the children in your life are especially lucky to have you in theirs.

YOU SHOULD TALK ABOUT YOUR CF IN A WAY THAT MEETS YOUR CHILD'S INDIVIDUAL NEEDS AND STAGE OF DEVELOPMENT. Telling your children about your CF gives them language to ask important questions, express their concerns, and talk to others about CF.

- **Call it “cystic fibrosis” or “CF.”** Honest, open communication is important. Your child is likely to hear medical terms — using the correct words for your illness and treatments from an early age can prevent your child from becoming confused.
- **Start talking about CF when your child is young.** The best person to teach your child about CF is you, the expert. It is natural to want to protect your child from a serious disease like CF, but it is best that your child learns directly from you rather than overhearing it or learning from other sources.
 - ♦ Receiving incorrect information about CF, or learning from someone other than you, could be scarier for your child than learning the truth directly from you.
- **Discuss changes in your health.** Any change your child notices is a good place to start.
 - ♦ “You may have noticed that Dad has been more tired recently. That’s because...”



“As my daughter became a teenager and my CF slowly progressed, I could see a growing concern in her eyes if I had to be admitted to the hospital or do home IVs. I would make sure to tell her that I would let her know if there comes a time to worry, but that time is not right now. I would reassure her by reminding her that I get my care from an amazing hospital with a wonderful CF team, and that I am doing everything the doctors are telling me to do.”

– Jennifer Bleecher, a mother with CF

- **Welcome your child’s questions, concerns, and worries.** Let your child know you are interested in discussing anything about your CF that they want to talk about.
 - ♦ “Tell me what you are wondering about. Is there something you want to know?”
 - ♦ It’s okay to say, “That’s a good question. Let me think about it and we can talk together later today.”
 - ♦ Tell your child that it is okay for them to be mad or to worry sometimes. “Yes, I wish this was not happening too. We will take it one day at a time.”
- **Don’t let your child worry alone.** Encourage your child to share their worries with you.
 - ♦ Children may read about CF online, in the media, or in books. It’s important to let them know that your experience may not be the same as someone else’s.
 - ♦ “How did watching that movie make you feel?”
 - ♦ “I am so glad you told me you are worried about my health. It can be scary to be alone with those feelings. I love that we can talk about this together.”

MANY PARENTS WITH A SERIOUS ILLNESS SAY THEIR CHILDREN'S QUESTIONS ABOUT THE POSSIBILITY OF DEATH ARE THE MOST DIFFICULT TO ANSWER. Avoiding or dismissing questions about death that children commonly have can leave them feeling alone, ashamed, or more afraid.

- **Children understand death differently depending on their developmental stage.**
 - ◆ Infants or toddlers have no concept of death.
 - ◆ Preschool-age children are curious about death and often imagine that it is reversible.
 - ◆ Elementary school-age children understand that death is permanent and often focus on specific facts.
 - ◆ Adolescents can understand death in a more complex way.
- **Ask your child to help you understand why they asked this question.**
 - ◆ Is there a specific worry? Did they overhear someone? Did they Google or read something?
 - ◆ Exploring in more detail shows that it is safe to talk about their concerns with you.
- **It is wise for the answer to be fundamentally truthful.**
 - ◆ It is okay to realistically acknowledge that future health is not guaranteed.
 - ◆ You might say, *"No one is worried about me dying now. I am planning on and doing all I can to live a long, long time."*
- **Balance uncertainty with reassurance.**
 - ◆ Sharing the goals of your current CF treatment and explaining how treatments are managing your CF can reduce the worry associated with uncertainty.
 - ◆ *"I hope this new medicine will help me breathe more comfortably so I have enough energy to go to your soccer game this weekend. If I don't feel up to it, Mom will take videos so we can watch them together."*
 - ◆ *"I have to stay in the hospital longer. My CF team is doing everything they can to help me feel better."*



TO LEARN MORE

Visit the CF Foundation's website for information on parenting at:
[cff.org/Life-With-CF/Transitions/Family-Planning-and-Parenting-With-CF/Parenting-as-an-Adult-With-CF/Planning-Ahead-and-What-to-Expect/](https://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/)

FOR SUPPORT

CF Peer Connect: [cff.org/PeerConnect](https://www.cff.org/PeerConnect)

FOR QUESTIONS

Call **1-800-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.

