

PARENTING AS AN ADULT WITH CYSTIC FIBROSIS: BALANCING FAMILY LIFE AND CF

A GUIDE FOR PARENTS
WITH CYSTIC FIBROSIS

Parenting is always a balancing act, and parenting with cystic fibrosis brings more responsibilities and things to think about. These may include balancing enjoying parenting with maintaining your health, doing treatments, and supporting the children you love when you don't feel well. The following suggestions also may help someone caring for a child whose parent has CF, and adults with CF who play a significant role in a child's life.

WHEN CF IS PART OF YOUR DAILY LIFE, IT IS PART OF YOUR FAMILY'S LIFE TOO.

- You can make your CF care routine normal to your child by doing airway clearance and taking medications in front of them starting when they are young. Tell them what you are doing and why. This will help your child learn about CF early.
- Find small ways to involve your child during your treatments. Many children enjoy helping; for instance, by pressing start on the vest. Their interest in being included may change over time as they grow and develop.
- Some parents bring their child to CF clinic visits so they can ask questions. After visits, you can see if there is anything they need help understanding.
- An additional benefit of doing your treatments consistently is that it shows your child how important it is to take care of themselves.



"I did all of my CF care in the living room to help normalize it for my daughter, and it also provided opportunities for her to ask me questions. When she was fairly young, I remember her asking what my nebulizer treatments were. I explained to her that it helped me breathe better and helped my cough. I found that when I was honest with her, it helped build her trust while also encouraging her to ask me questions."

– Jennifer Bleecher, a mother with CF

YOU AND YOUR CHILD MAY NEED ADDITIONAL STRATEGIES TO COPE IF YOUR HEALTH GETS WORSE, SUCH AS DURING AN EXACERBATION OR HOSPITALIZATION.

Keep your child's daily schedule and routines the same as much as possible to provide stability.

- Share your child's routine and preferences with others.
 - ♦ Add your child's events to a shared calendar to allow others to step in and help with care.
 - ♦ List daily routines, how to contact your child's teachers, coaches, friends and their parents, and other special information so people providing support have access to it.
- Use caregivers your child knows to bring stability and predictability.
 - ♦ Tell your child who will be caring for them and taking them to their activities.
- Tell your child how you will stay in touch with them when you are in the hospital, such as through phone or video calls.

“Whenever my mom was sick or had to be hospitalized, she always made sure that my routine stayed consistent. My dad or grandma would come over and take on her role in the house, and my mom always made sure they were aware of my schedule. My mom and I would plan a time to talk on the phone. It was helpful for me to hear from her and stay connected even though she wasn’t home.”

–Claudia Hannum, a daughter of a mother with CF

Organize a support team to help.

- Ask someone to manage information.
 - ♦ Keeping everyone informed can become overwhelming. Assign a person, such as a relative or close friend, to manage updates about your health.
- Ask someone to organize support.
 - ♦ Pick someone to field offers of support and give volunteers specific tasks.
- Delegate routine tasks to others.
 - ♦ As you decide what to accept help with, save your energy for doing things where your involvement is essential.
 - ♦ Let others handle tasks like grocery shopping or laundry. Kids like to help too!
- Plan a hospital visit to help your child stay connected and less worried.
 - ♦ Talk with your medical team about good times for your family to visit.
 - ♦ Ask supportive adults to go to the hospital with your children so they can prepare your child before they arrive, can take your child home if the visit becomes more than your child can manage, and talk with your child afterward to address any confusion or worries.



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/

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

FOR SUPPORT

CF Peer Connect: 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.