

Stress in Families of Children and Adolescents with Cystic Fibrosis (CF)



Stress involves a variety of negative thoughts, feelings, and reactions that accompany difficult situations. Everyone experiences stress as a natural part of life. However, young people living with CF and their families experience uniquely challenging circumstances and demands. This handout can assist parents and caregivers with understanding and managing common stressors.

What Are Some Causes of Stress Related to CF?

Everyone's experience is unique, but some common sources of stress for children with CF are:

- Disruptions to school and other activities
- Time-consuming daily treatments
- Anxiety and discomfort associated with medical procedures
- Self-consciousness around differences related to CF

As they grow up, individuals with CF go through many physical, intellectual, social, and emotional changes as part of normal development. Special challenges for adolescents and young adults with CF may include:

- Developing a sense of self and figuring out how CF fits in
- Becoming more responsible for daily CF care
- Balancing a personal need for increased independence with the need for caregiver support
- Disclosing a CF diagnosis—to friends, schools, partners, employers, and others
- Managing CF when starting college or work
- Transitioning from the pediatric to the adult CF clinic
- Dealing with uncertainty when considering the future, such as planning for education, career, or family building

The whole family may also be managing additional stressors:

- Financial burden from health care costs
- Struggles with insurance coverage
- Strain on family relationships
- Developing and maintaining trust in each other, and in your CF care team

What Are Some Signs of Stress?

There are many natural responses to stress, including:

- Emotions—feeling sad, anxious, overwhelmed, guilty, angry, or impatient
- Physical responses—feeling tense, restless, or fatigued, having stomach aches or headaches
- Thoughts—worries, difficulty concentrating, or self-critical thoughts
- Behavior—social withdrawal, difficulty completing tasks or with self-care

Signs of stress differ from person to person, and based on one's age or developmental stage.

In young children:

- Increasing clingy behavior or separation fears
- Demanding that things be a certain way
- Tantrums or defiant behavior
- Changes in sleep, appetite, or eating patterns
- Frequent stomach aches, headaches, and other aches and pains

In older children, adolescents, and young adults:

- Changes in mood or increased anxiety
- Decreased motivation for CF self-care
- Irritability or impatience
- Negative thinking and low self-esteem
- Difficulty concentrating or completing assignments
- Avoiding or procrastinating with tasks or clinic appointments
- Less interest in social activities
- Risky behavior or using illicit drugs, alcohol, or tobacco

What Can I Do to Help?

Emotional well-being is an important part of overall and family health. Here are some ways for individuals and families to practice emotional self-care and promote resilience for coping with stress:

- 1. Practice acceptance.** Situations that your family may be facing are hard. It can be important to acknowledge and honor the feelings that you and others are experiencing before moving on to the next step to ask, *What can I do now?* Parents can help by naming emotions for young children, and by providing the space to share feelings while listening calmly and without judgment for children of all ages.
- 2. Break down problems and tasks into manageable parts.** This is a skill that gets better with practice and support.
- 3. Establish daily structure and routine.** Routines help people of all ages stay physically and emotionally balanced. Knowing what to expect can reduce anxiety. Routines provide structure that can help your family keep up with daily CF care and self-care.

4. Encourage healthy habits. These may include getting physical exercise, eating healthy foods, and keeping healthy sleep habits. Healthy sleep is key for maintaining emotional well-being. Experts recommend going to bed and waking up at the same time each day, and turning off electronics (phone, tablet) at least a half hour before bedtime.

5. Practice relaxation or mindfulness. These can put the brakes on the body's response that accompanies stress. Relaxation and mindfulness are learned skills, but anyone can do them, and there are lots of ways to practice. Many free resources and apps are available—see what works for you. Practicing relaxation or mindfulness can be an individual or family activity.

6. Build a support network. Identify sources of support for each member of the family, and get additional help when needed. Parents are the primary source of support for reducing the impact of major stress on children. Parents can also be a model to their children by making emotional self-care a priority. (For more tips on emotional self-care, please see the handout, *Stress Among Adults with Cystic Fibrosis (CF) and Their Loved Ones*, in this series).

7. Practice mindful awareness and recognize moments of joy. Even in the most difficult times, it's possible to experience moments of beauty, happiness, humor, and personal connection. These moments can get lost in a busy or stressful day.

Take a few minutes to write down one or two moments where you felt good. These are typically small moments, like noticing signs of spring, laughing at a funny message that a friend sent, or having a good hug. This can be a fun family activity or daily bedtime routine where each person says or writes down their “moment of joy.” These “moments” can be collected in a box or jar to provide a visual reminder of how many you have as a family, and to be read and enjoyed at a later time.

What Can My CF Care Team Do to Help?

Your CF team wants to support the emotional well-being of individuals with CF of all ages and their families. They understand that new challenges and concerns may come up, or old stressors can reappear from time to time. Communicate regularly with your CF team about what is going well and what has been difficult.

If anyone in your family is experiencing symptoms of stress, anxiety, or depression that are persistent or are interfering in CF care, school, work, or the enjoyment of life, it's important to let your CF team know. Depression and anxiety are common and not surprisingly—given the additional stress that accompanies living with a chronic illness—more common in individuals with CF and their caregivers. **The good news is that treatment for anxiety and depression works.** Your CF team can provide support and connect you with an appropriate referral.

In Case of An Emergency

If your or your child's level of distress is so high that you can't wait for a call back from your care team, please call 911 or go to your nearest emergency room. The following resources are also available via phone and online chat at any time:

The National Suicide Prevention Lifeline:

1-800-273-8255 or suicidepreventionlifeline.org/chat/

Your call is answered immediately and gets routed to a regional or local crisis center that is staffed with trained individuals who provide confidential emotional support to everyone who calls. The call and service are both completely free. You don't have to be feeling suicidal in order to use this service—it's for anyone experiencing emotional distress.

Crisis Text Line – Text HOME to 741-741