

Stress Among Adults with Cystic Fibrosis (CF) and Their Loved Ones

Stress involves a variety of negative thoughts, feelings and reactions that accompany difficult situations. Everyone experiences stress as a natural part of life. However, adults living with CF, as well as their spouses, partners, or caregivers, face uniquely challenging circumstances and demands.

What Are Some Causes of Stress Related to CF?

Everyone's experience is unique, but some common sources of stress are:

- Exacerbations, hospitalizations, and medical procedures
- Clinic appointments and getting pulmonary function tests (PFTs)
- Time-consuming daily treatments
- Financial stress
- Disruptions to or limitations in engaging in school, work, or other valued activities
- Struggling with one's "place" in life or sense of life direction
- Dealing with uncertainty when considering the future, such as planning for education, employment, or family building
- Worry about disease progression and coping with advanced disease
- Balancing self-care and care for others
- · Loss, grief, and "survivor's guilt"
- Not being able to access or benefit from breakthrough medications
- Low self-esteem and doubts about self-worth
- Developing and maintaining trust in yourself, your caregiver, your family, and your 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 selfcritical thoughts
- Behavior—social withdrawal, difficulty completing tasks or self-care, using alcohol or other substances

What Can I Do to Help?

Emotional well-being is an important part of overall 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 you and your spouse, partner, caregiver, or family may be facing are hard. It can be important to acknowledge and honor the feelings that you or others are experiencing before moving on to the next step to ask, What can I do now? Provide the space to share feelings while listening calmly and without judgment.
- 2. Break down problems and tasks into manageable parts. Looking at a problem or task as a whole can feel overwhelming. Breaking it down can reduce stress, help you avoid procrastination, and lead to greater confidence.

- 3. Establish daily structure and routines. Routines help people to stay physically and emotionally balanced. Knowing what to expect can reduce anxiety. Routines also provide structure that can help you keep up with daily CF 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. Use an app such as Fabulous Daily Self Care to help track personal health goals.
- 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, partner, or family activity.

- 6. Maintain a support network. It's important to identify sources of support and get additional help as you need it. Make emotional self-care a priority.
- 7. Be intentional about preserving closeness in your relationships and friendships. Plan activities with friends and loved ones and find new activities to bond over, such as watching a new show together or doing a painting class on YouTube. Practice physical closeness by hugging or sitting close to a loved one.
- 8. Monitor your stress and coping responses.
 Increasing awareness is a powerful stressmanagement strategy. You can ask yourself these questions: In what ways does stress impact me (my emotions, thoughts, physical responses, actions)?
 How do others notice I am stressed? What do I do that helps me to cope? Is there anything else I want to try to do more often to take care of my emotional health, or do I want to try something new? Try keeping track of your stress and coping responses using the log below. Then, you can practice responding differently to a stressful situation and notice if it helps.

STRESS AND COPING TRACKER											
Use this scale to rate your level of stress											
	1 at all essed	_ 2	_ 3	4	5	6	7	8	9	10 As str as you	essed u can be

Stressful Situation/ What Happened?	STRESS LEVEL (1-10)	EMOTIONS: What was I feeling?	COGNITION: What was I thinking?	ACTIONS: How did I respond? What was I doing?	COPING RESPONSE: Did I do anything that was helpful to manage the stress?

9. Practice self-compassion. Are you being too hard on yourself? Many people notice that they are sometimes their own worst critics. We all have bad days, and everyone is simply doing the best they can. Self-criticism drains energy and rarely motivates anyone to improve a situation. You can start practicing self-compassion by noticing the way that you talk to yourself. Self-critical thoughts can often appear in the form of should statements, such as I should be doing better. If you notice these types of thoughts, you can try asking yourself these questions: Am I blaming myself for something that is not 100% in my control? Can I think about this in a way that is still realistic but is kinder to myself? (For example, I wish I was able to do this differently, but there are a lot of reasons that this situation is difficult that have nothing to do with me). Consider how you would treat a friend in the same situation. What would you say to them? Use positive self-talk with the same love and support you would give to a friend. You can enhance this practice by writing down your self-critical thoughts; this can help create some mental distance from them. Then, try writing down the new, more helpful and less selfcritical ways to think about a situation. Read your new statements aloud to yourself and see how they change the way you feel.

What Can My CF Care Team Do to Help?

Your CF team wants to support the emotional well-being of all individuals with CF and their caregivers. 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 you, or a close caregiver such as your spouse, partner, or parent (even now that you are an adult) are experiencing symptoms of stress, anxiety, or depression that are persistent or interfering in CF care, school, work, or enjoying life, 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 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 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





