

# CF AND MENTAL HEALTH: BUILDING RESILIENCE

A GUIDE FOR PARENTS  
AND CAREGIVERS

## THE IMPORTANCE OF CARING FOR THE CAREGIVER

Living with cystic fibrosis or caring for someone with CF is stressful. Symptoms, treatments, and associated costs can be a source of worry for people with CF and their caregivers. Caregivers may include biological, adoptive or foster parents, grandparents, partners or spouses, extended family members, or even close friends who participate in the regular day-to-day care of someone with CF.

At times, CF can make daily activities, like going to work or school, socialising with family and friends, and managing finances, more difficult for either the individual with CF or their caregivers. Over time, these stressors can have a negative impact on mental health and well-being for families affected by CF.

Practising self-care, or activities intended to take care of our physical, emotional and spiritual health, build personal resilience and play an important role in managing CF care successfully. Effective self-care prevents stress from becoming overwhelming and may protect caregivers from developing more persistent symptoms of anxiety or depression.

Research shows that caregiver depression and anxiety can negatively affect CF patients' health outcomes, including lower body mass index (BMI), decreased lung function (FEV<sub>1</sub>), increased frequency of hospital admissions, increased anxiety and depression, and decreased quality of life.<sup>1</sup>

When caregivers of children practise self-care, it sets a good example for their child or teenager with CF. This is one of the best ways caregivers can teach a child or teen with CF to value their health and wellness as they move into adulthood.

Taking time for self-care is not selfish; it is necessary to help and care for others well. When practising self-care seems the most challenging, it is often when these activities are most needed. Receiving help and support is a healthy and necessary part of managing the complexities of CF.

### Common CF Stressors

- New CF diagnosis
- Time-consuming treatments
- Lung infections
- Lung function tests and results
- High calorie requirements for maintaining weight
- Sputum culture results
- Hospitalisations
- Doing home IV antibiotics
- New feeding tube
- CF-related diabetes diagnosis
- Access to medications

## EXAMPLES OF SELF-CARE

PHYSICAL	EMOTIONAL	SPIRITUAL
<ul style="list-style-type: none"> <li>· Eat a healthy, balanced diet</li> <li>· Get 7-8 hours of sleep each night</li> <li>· Exercise a few times a week (brisk walking, jogging, biking, etc.)</li> <li>· Limit screen time</li> <li>· Get outdoors a few minutes a day for fresh air and natural light</li> <li>· Focus on preventive medical care in addition to CF care</li> </ul>	<ul style="list-style-type: none"> <li>· Stay connected to supportive people</li> <li>· Delegate tasks to others</li> <li>· Ask for help before feeling overwhelmed</li> <li>· Express emotions through healthy outlets</li> <li>· Learn to recognise and stop negative thinking patterns</li> <li>· Establish boundaries; say "no"</li> <li>· Schedule time for fun and use humour</li> <li>· Celebrate life milestones</li> </ul>	<ul style="list-style-type: none"> <li>· Make time for quiet reflection</li> <li>· Practise gratitude</li> <li>· Keep a journal</li> <li>· Attend a worship service</li> <li>· Allow time for play and creativity</li> </ul>

## WHAT RESILIENCE MEANS FOR CAREGIVERS

The American Psychological Association defines resilience as the ability to “bounce back” from a stressful circumstance. People who face difficult life circumstances, such as caring for a loved one with a significant medical illness, commonly experience sadness and emotional pain. Resilience is not the absence of difficulties, but a capacity for personal strength that we all have and can build.<sup>2</sup> Building resilience means learning useful thoughts and actions in response to stressful events and circumstances.

When caregivers care for their own physical, emotional, and spiritual needs, they build resilience and improve their overall mental health. Mental health encompasses a person’s overall wellness, ability to reach one’s potential, and ability to manage life stress.<sup>3</sup>

One way to think about stress and resilience is that they are like opposite ends of a scale. Even the *smallest* effort in caring for the caregiver can help tip the scale in the direction of resilience.

Developing ways to care for oneself is an ongoing process and may need to increase or change when stressors increase. For example, when there is a new CF complication or change in health status, self-care activities may need to be increased to counter-balance the negative impact of stress.

Most paediatric CF clinics offer a brief screening process for parents/caregivers to help determine if they may be experiencing overstress. A CF social worker or psychologist, therapist, or primary care physician are a few examples of skilled professionals who can help caregivers develop a plan for self-care. Build resilience by caring for the caregiver!

## ADDITIONAL CF CAREGIVER RESOURCES

Please visit the Cystic Fibrosis Foundation website for additional resources. The following information can be found in the Emotional Wellness section.

[www.cff.org/Life-With-CF/Daily-Life/Emotional-Wellness/Coping-While-Caring-for-Someone-With-Cystic-Fibrosis](http://www.cff.org/Life-With-CF/Daily-Life/Emotional-Wellness/Coping-While-Caring-for-Someone-With-Cystic-Fibrosis)  
[www.cff.org/Life-With-CF/Daily-Life/Emotional-Wellness/Depression-and-CF](http://www.cff.org/Life-With-CF/Daily-Life/Emotional-Wellness/Depression-and-CF)

Written by Shaina Blair, LCSW, Children’s Healthcare of Atlanta and Carolyn Snell, Ph.D., Boston Children’s Hospital. Approved by the Cystic Fibrosis Foundation Mental Health Advisory Committee. This information meets the guidelines and standards of the Cystic Fibrosis Foundation’s Education Committee.

### References

1. Quittner AL, Barker DH, Snell C, Grimley ME, Marciel K, Cruz I. Prevalence and impact of depression in cystic fibrosis. *Curr Opin Pulm Med*. 2008 Nov;14(6):582-8. PMID: 18812836
2. American Psychological Association. The Road to Resilience. <http://www.apa.org/helpcenter/road-resilience.aspx>. Accessed on December 14, 2017.
3. World Health Organization. Mental health: strengthening our response. <http://www.who.int/mediacentre/factsheets/fs220/en/>. April 16, 2016. Accessed on December 14, 2017.



For questions, call + 61 02 9889 5171

or email [CFA1@cfa.org.au](mailto:CFA1@cfa.org.au).

This handout is adapted for Cystic Fibrosis Australia (CFA) with permission from Cystic Fibrosis Foundation (CFF).

