
May is Cystic Fibrosis Awareness and Mental Health Awareness Month

Mental health care is an important part of living with CF, as people living with cystic fibrosis and their caregivers are at an increased risk for depression and anxiety compared to the general population. Many people living with CF have experienced medical trauma, from painful medical procedures or similar experiences, and have also shared about their experience of survivors' guilt: complicated grieving for beloved CF community members whose lives have been lost. All of these experiences can lead to feelings of anger, grief, guilt, numbness and isolation. Mental health disorders and the emotional toll of living with CF may negatively impact quality of life, treatment adherence, lung function, body mass, and hospitalization rates.

Please note that the following resources are educational resources, not medical advice. **If you're struggling with your mental health, talk to your CF care team or a trusted medical professional.**



High Need: Individual Therapy

If your mental health needs are high (maybe you're feeling very stuck, depressed, anxious, or numb), then **Individual Therapy** might be for you. This is the classic one-on-one therapy that you've seen in movies, etc. where you have regular (usually weekly) sessions with a licensed provider (social worker, therapist, psychologist, psychiatrist, or another mental health professional). Many providers will offer a telehealth/remote option if that's more convenient for you.

If you're open to learning about whether medication might also help, then meeting with a psychiatrist or psychiatric nurse, or just talking with your regular doctor could be useful.

The website Psychology Today has a tool so you can search for care providers by profile, insurance coverage, type of therapy, telehealth vs in person, and other factors.

CFRI offers financial support for therapy through their Counseling Support Program.

Moderate Need: CF-Specific Resources

If you're interested in CF-specific mental healthcare, ask your CF team mental health coordinator about ACT with CF, CF Cognitive Behavioral Therapy (CBT), or other CF-specific resources.

CFRI offers support groups led by social workers and health professionals for the CF community, including adults living with CF, caregivers, and other specific groups. There are also Facebook support groups: CF support, parent support, and parents of newly diagnosed children.

Johns Hopkins Cystic Fibrosis Center has a dedicated page to mental health and CF, which has information and resources for patients and families.

Low Need: Everyday Support

The virtual world is full of tools to help with everyday wellness and self-care. While these tools do not replace professional care, they may help to support your mental and emotional wellbeing.

For meditation and mindfulness exercises:

- Apps: Insight Timer, Calm, Headspace, Sanvello
- UCSF mental health resources
- CF Yogi provides free yoga classes for the CF community
- CFRI offers online mindfulness and wellness classes
- A journal like Commit30 has specific prompts and reminders for self-care and other goals.
- University at Buffalo School of Social Work Self-Care Plan