DEPRESSION, ANXIETY and CYSTIC FIBROSIS

WHAT THE GUIDELINES MEAN FOR YOU

People with cystic fibrosis and parents who take care of children with CF are two to three times more likely to experience depression, anxiety or both, compared to people in the general population.*

Guidelines were published to help CF care teams provide effective care for people with CF and their families with depression, anxiety or both.

Moments of sadness and anxiety may come and go, however depression and persistent anxiety should be treated as part of your overall health and emotional well-being. Here you find more information on what depression and anxiety is and what you and your CF team can do.



WHAT IS DEPRESSION?

Depression is a common mental health condition that negatively affects the way you feel, think and act. Unlike occasional sadness or feeling blue, clinical depression can last for a long time—weeks, months or years—if not treated. People who have depression can have extended periods where they feel hopeless and lose interest in things they normally would enjoy. They may also experience eating and sleeping problems.

WHAT IS ANXIETY?

Anxiety is a natural emotion that can come and go in response to fears or worries about such things as changes in health, work, relationships or money. A person may have an anxiety disorder if the anxiety does not go away, gets worse over time and prevents them from participating in ordinary daily activities.

In addition to the generalized anxiety many people with CF and their family and/or caregivers may experience, some people also experience a very specific form of anxiety such as that centered on medical procedures.

Always seek help!

Untreated depression, anxiety or both can affect both your physical and emotional health. In addition, it may interfere with your ability to take care of yourself or your child.

Feeling blue or anxious sometimes is understandable. Feeling depressed or anxious for a long time is not. Do not dismiss depression and anxiety that do not go away as being part of CF. Although these feelings are very common, they can be treated. Take good care of yourself and get help.

WHAT CAN YOUR CF TEAM DO

The Cystic Fibrosis International Guidelines Committee (sponsored by the Cystic Fibrosis Foundation and the European Cystic Fibrosis Society) recommends the following for screening and treating depression and anxiety as part of comprehensive CF care:

- **Prevention:** Your CF care team will work with you on effective ways to manage stress and provide ongoing age-appropriate information on how to cope with a chronic disease like CF.
- Screening: If you have CF and are at least 12 years old, or if you are caring for someone with CF who is age 17 or younger, you will be asked to complete two short screening surveys.
- Advice: If the survey results suggest you are struggling with depression, anxiety or both, your CF care team may recommend further evaluation and/or may recommend treatment. They will always discuss this with you. It is your choice what to do.

BEGINNING SIGNS OF DEPRESSION OR ANXIETY WHAT YOU CAN DO:

If you have mild symptoms or recognize the beginning signs of depression, anxiety or both, talk to your CF team. They can work with you to maintain your emotional health.

The following are ways that you can prevent problems with depression or anxiety from getting worse and minimize their impact.

- Talk with somebody, preferably in person. Many people with depression withdraw and isolate themselves from other people.
- Talk to someone on your CF team, your general practitioner or a psychologist. Many people tend to wait to get help because they think their problem isn't serious enough. Prevention is always better.
- Realize you are not alone. Many people, and especially people with CF, experience these problems.
- If you are thinking about suicide, talk to someone. Call your general practitioner for help.
- Spend time with people who lift your spirits.
- · Avoid alcohol or drugs.
- · Continue your CF treatment plan.
- Practice good sleep habits. Do your best to get enough sleep. Go to bed and wake up on a consistent schedule. Avoid staying in bed when you are not sleeping.
- Get outside in nature for 30 minutes every day.
- · Make time for things you enjoy.
- Be physically active. Exercise can help reduce stress.
- Practice relaxation techniques.
- Avoid caffeine and cigarettes, which can increase anxiety levels.
- Join a support group. Talking about your problems with people who have the same experience can help you feel less alone.

These activities are not a substitute for professional care, but can make a real difference in your mood.

WHAT ABOUT INSURANCE COVERAGE?

The types of insurance coverage available will vary in each European country depending on the health care system in place. We advise you to talk to your health insurance company or to your CF team about insurance coverage for mental health care.

TO LEARN MORE

This patient information leaflet is adapted for the ECFS website with permission from the CFF.

View the CF Foundation and ECFS Guidelines at <u>https://www.ecfs.eu/mentalhealth</u>

