

To Our Patients and Families:

As we continue to strive to provide the best possible care for our CF families, we will be implementing new recommendations of the International Committee on Mental Health in CF beginning [INSERT date here]. In 2013, the Cystic Fibrosis Foundation (CF Foundation) and the European Cystic Fibrosis Society put together a team of experts to form this Committee, established to help CF Centers address anxiety and depression in individuals with CF and their parents/caregivers. The CF Foundation is now recommending that each CF Center offer screening for anxiety and depression to all patients ages 12 and over and to parents/caregivers of children from birth to age 17 at least once per year.

Research shows that individuals with CF experience anxiety and depression at a rate that is 2-3 times higher than those in the general population<sup>1</sup>. This is also true for their caregivers. People experiencing anxiety and/or depression may have a harder time getting treatments done, their health tends to be poorer, and they are more likely to experience struggles in school, work and relationships. Though we all experience some worried or sad feelings at times, anxiety and depression that doesn't go away can interfere with daily activities and worsen overall quality of life.

What does screening mean for you?

- At an upcoming clinic visit, patients 12 years and older and parents/caregivers of all pediatric patients will be offered the opportunity to complete two simple screening tools called the Patient Health Questionnaire and the Generalized Anxiety Disorder Screener. The questionnaires consist of 9 and 7 questions and should take no more than 3-5 minutes total to complete.
- A qualified staff member will share the results with you and/or your child. If there are concerns based on the results, the medical team will work with you and your family to find the best solution to address these concerns.

These questionnaires are optional, but we hope that by identifying symptoms of anxiety and depression early through screening, then providing supportive education and linkage to helpful services, we can work to improve health and quality of life for all of our patients and their families. *Please see the enclosed information sheet for details on CF mental health research and the process for mental health screening in clinic.*

We are glad to answer any questions you may have about these new guidelines. Please do not hesitate to contact us, as we value your input. You may contact [INSERT clinic staff contact info here] for more information or discuss this with the team in clinic.

We look forward to seeing you at your next visit!

Sincerely,

Your CF Care Team

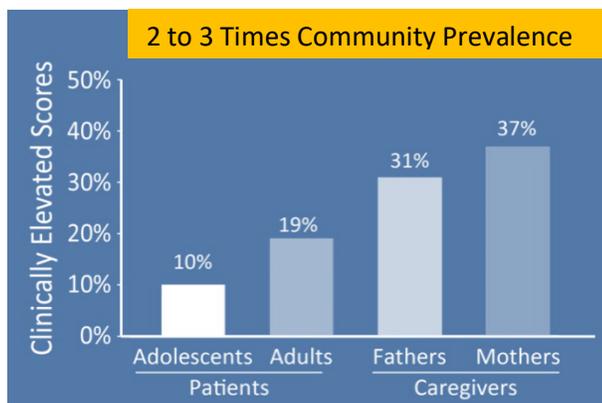
<sup>1</sup> Quittner, et al. Thorax. 2014; 69(12): 1090-7.

## CF Mental Health Research

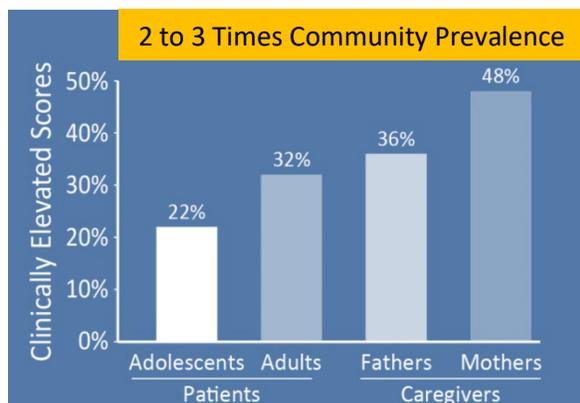
A recent international study was conducted exploring depression and anxiety symptoms in individuals with CF and their caregivers. Study participants were recruited from 45 CF care centers in the US and CF centers in eight European countries. Participants completed reliable questionnaires designed to identify symptoms of anxiety and depression.

### Research Results

- Teens and adults with CF were 2-3 times more likely to experience symptoms of depression and anxiety than people who do not have CF.
- Rates were similar for parents/ caregivers (including both mothers and fathers) of people with CF.
- Adolescents were more likely to have elevated depression and anxiety scores, if they have a caregiver experiencing significant symptoms.



**Table 1. Depression**



**Table 2. Anxiety**

Quittner, et al. Thorax. 2014; 69(12): 1090-7.

### Mental Health Screening for Children/ Teens with CF

- At least once a year, patients 12 and over will be asked to complete two simple validated screening tools . Questionnaires take about 5 minutes to complete.
- Screening results will be shared with you and your child during the course of a routine clinic visit.
- If there are concerns based on screening results, our staff will work with your child/ family to provide individualized education on coping techniques and/or coordination of referrals to address your child's specific needs.

### Mental Health Screening for Caregivers

- If your child is 17 years or younger, you will be offered the opportunity to complete two simple screening tools. Questionnaires take about 5 minutes to complete.
- If there are concerns based on screening results, our clinic staff will share these with you *privately* and provide supportive education, information on coping techniques and referral information.