HEALTH IS A STATE OF BODY. WELLNESS IS A STATE OF BEING

J. Stanford, 31 March 2014

A Focus on Emotional Health While Living with Cystic Fibrosis
Why are we talking about mental health and CF?

- CF is a Multi-system disease that affects every area of your body and your life.

- Despite new drugs to “modify” the effects of this disease, management of CF is complex and time consuming (averaging 2-4 hours per day). As a result, CF continues to be one of the most difficult chronic conditions to manage.

- Studies measuring psychological distress in individuals with CF, and their parent caregivers, have found high rates of both depression and anxiety.

- Psychological symptoms in both individuals with CF and caregivers have been associated with decreased lung function, lower BMI, worse adherence, worse quality of life and more frequent hospitalizations. (Quittner AL, et al., 2015)
Why are we talking about mental health and CF?

- The TIDES study was an international study, sponsored by the CF Foundation and the European CF Society, which looked at the prevalence of anxiety and depression in CF.
  - Screened over 6000 patients ages 12 and older and 4000 parents.
  - Indicated higher rates for both depression and anxiety
  - Higher rates of anxiety
- Important Finding: When parents report elevated depressive or anxiety symptoms, their adolescent with CF is more than twice as likely to experience depression and anxiety (Quittner AL, et al., 2015).
Prevalence of Depression 2-3 Times Community Prevalence

Prevalence of Anxiety 2-3 Times Community Prevalence
International Committee on Mental Health in Cystic Fibrosis

A panel of experts worked together over 18 months to
* Review the research
* Develop recommendations for clinical care

The Panel developed 15 recommendation statements for screening and treatment of depression and anxiety in individuals with CF and parent caregivers (Quittner AL, et al., 2015).

CONSENSUS STATEMENT

Periodic screening of depression and anxiety symptoms and appropriate interventions can significantly improve quality of life and health of individuals with CF and their parent caregivers (Quittner AL, et al., 2015).
All CF Centers have been asked to provide ongoing support and education to all patients and families to promote stress management, health coping skills, etc.

The Cystic Fibrosis International Guidelines Committee recommends the following for screening and treating depression and anxiety as part of comprehensive CF care:

- Learning new coping skills
- Getting screened
- Getting help

All CF centers will initiate a screening program for anxiety and depression to include annual screenings during clinic visits conducted by the clinical social worker to all patients 12 years and offered to parent caregivers of patients 0-17 years old. (Parent/family screening is optional)

- PHQ-9 to screen for depression
- GAD-7 to screen for anxiety
Results and Next Steps

- **Results**
  - Normal Screening: proceed to get annual screening
  - Mild Range: receive supportive intervention and will be rescreened at next visit
  - Elevated range: receive clinical assessment and psychological and/or psychopharmacological interventions.

- Recommendations include a stepped care model for anyone who is experiencing higher than average levels of depression or anxiety.

- Recommendations also include detail on the types of therapeutic interventions that have been found to be the most effective.
What will this look like at my CF center?

- Our center received a grant for three years to help fund a screening and follow up program. This gives us the ability to:
  * Hire our social worker to work full time
  * Hire a psychologist to help with counseling needs
- Screenings will be kept confidential and will be repeated annually when “normal” or more frequently if elevated
- We will work closely with you to get additional support
Promoting emotional wellbeing

- **Foster resilience** through purpose, setting expectations, letting go and savoring the good
- **Self compassion**: Studies show that people who have compassion for themselves are happier, more optimistic and more grateful vs. self criticism: leads to higher rates of depression and stress, with less effective coping
- **Self acceptance** reduces your battle with yourself, frees you to be more peaceful and happy
- **Learn mindfulness** or relaxation practices that soothe and center you
- **Healthy Lifestyle**: Exercise, sleep and eat!
- “**Neurons that fire together, wire together**”....Change your thoughts and you will change how you feel
- **Be flexible** Expect the unexpected, redefine “success” to find your happiest life
- **Acknowledge fear** and develop inner strength
Be fearless, be brave, be bold, love yourself
A CF Patient

The source of my happiness lies within. It is an inside job.
Lisa McCrohan, barefootbarn.com

Inner strengths are the supplies you have in your pack as you make your way down the twisting and often hard road of life...
Rick Hanson, PhD

You are Stronger than you seem. Braver than you believe and smarter than you think
A.A. Milne

Hope is important because it can make the present moment less difficult to bear. If we believe that tomorrow will be better, we can bear a hardship today....
Thich Nhat Hahn
Financial Support: Individual Counseling Services For the CF Community

- Through the Cystic Fibrosis Quality of Life (CFQoL) program, individual therapy is available to children and adults with CF as well as to their family members (siblings, spouses and parents).

- The program addresses the impact of chronic illness on emotional health, including stress, depression, poor self-image, anger, and anxiety. Sessions are not limited to CF-related issues. Participation can improve health and quality of life.

- Select a licensed therapist in your community (e.g. LMFT, LCSW, LPC, psychologist). Ask your CF social worker if you need a referral. Psychiatric services are not eligible.

- CFRI will cover the cost of your insurance co-pay for five sessions. If you have no insurance, CFRI will pay up to $120 per session for five sessions.

- Your selected therapist MUST contact CFRI prior to providing subsidized sessions. Without the necessary completion of forms and authorization by CFRI, we are unable to reimburse therapists for their time.

- By participating in the CFQoL program, you are committing to take part in the brief evaluation process.

- This financial support will be available through December 2016, or until all funds are expended, whichever occurs first.

For more information contact Siri Vaeth Dunn: 650.665.7565 or svdunn@cfri.org
www.cfri.org
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"You are not your illness. You have an individual story to tell. You have a name, a history, a personality. Staying yourself is part of the battle."

~Julian Seifte