5 Questions for Parents of CF Teens

As parents of kids with CF, we can make a life-transforming difference by focusing as much on their mental health as we do on their physical health. If you think your child's CF is taking an emotional toll, asking yourself these questions may help.

By Lisa C. Greene, M.A., CFLE

Not too long ago I had a conversation with an amazing dad who is concerned about his 15-year-old daughter. She has cystic fibrosis and it's <u>taking a toll on her emotionally</u>. She's been hospitalized a lot and is not doing well at school. He is afraid that she is giving up, and he needed ideas for how to turn it around.

Certainly there are no easy answers here, but if you are the parent of a teen with CF and can relate to this dad's experience, here are some questions that may help.

- **1. First, is your child depressed?** Working closely with your child's care team, you may consider taking your child to a professional who is experienced with working with people who have chronic illnesses. They can identify whether or not your teen is <u>clinically depressed</u> or if she is "simply" disheartened. People with chronic illnesses, such as CF, have a higher rate of depression and <u>anxiety</u>. Getting professional help early is the first line of defense.
- **2.** What brings your child joy? Without having something to look forward to in life, people get tired of living. Sometimes it takes a little effort to figure out what brings your child joy.

I worked with one mom whose 14-year-old son with CF was struggling emotionally. She knew that he loved animals, so this mom made arrangements at the local zoo for her son to volunteer periodically. This really helped give him something to look forward to and work toward as a possible career down the road. It gave him just enough hope and joy to get through some rough spots.

3. Are you purposeful about having fun and connecting as a family? With our own two kids who have CF, we have always made it a priority to have fun as a family. It's not always easy; we have to <u>drag around a lot of medical equipment</u> everywhere we go. But it's a priority for us, so we do what it takes.

After medical <u>clinic visits</u> when our kids were little, we'd go to the zoo, a children's museum, a park or out to somewhere fun for lunch. We still go out after clinic when we can. When our daughter was hospitalized for several days, we "busted" her out of the hospital (with permission) to see the premiere of "The Hunger Games" with her friends.

Everyday life affords many opportunities to make memories. Studies have shown that investing more time, energy and money in life experiences, i.e., "having fun," makes you happier than

buying "stuff." I believe this approach has been a big part of our kids having a good attitude about cystic fibrosis, enjoying their lives and being connected as a family.

Family traditions, time together, fun experiences ... these are the things that lend a sense of hope and meaning, especially during the hard times.

- **4. Does your teen have a vision for his or her life?** Sometimes when kids have a serious and progressive chronic illness like CF, they have a hard time seeing past the illness to a future. It's important that we encourage and empower our children to dream and plan. With many illnesses, including CF, there is so much hope for the future!
- **5.** Can you connect your child with a good role model? Sometimes when a parent tries to encourage their teen directly, the child dismisses what their parent has to say with, "You don't understand. You're not the one with CF." In these situations, it can really help to share positive, powerful role models who are as much like the child as possible.

And by the way parents, what brings *you* joy? Are you <u>taking good care of yourself</u>, making sure you get your batteries recharged and having fun every now and then? Do you have a sense of purpose and meaning for your life (outside of living for your children)? Your positive example speaks more than words and lectures.