5 Ways Parents Can Foster Hope in CF Teens

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Parents of teens with cystic fibrosis often ask what they can do to help their child who is struggling to come to grips with their disease or is simply going through a rough patch. As a certified family life educator and the mother of two teens with CF, I believe caring for children's emotional wellbeing is just as important as caring for their physical health. Here's some of my best advice to help you support your child through good days and bad.

1. **Help your teenager begin to make specific plans for the future, including career planning.** Teens typically start the career exploration and planning process when they're in high school. Encourage your teen to participate fully. Don't let his or her illness be an excuse not to do something that is even remotely within the realm of his or her possibilities.

   Ask your teen: “If you didn't have CF, what would you want to do with your life?” Even if your teen can't be exactly what they want to be, they might be able to still participate in another way. For example, maybe your teen can't be a firefighter but they can still work directly with firefighters in any number of capacities. Help your teen explore options, interview people and get creative.

2. **Help your teen find ways to contribute to someone or something outside of themselves.** When a child has a chronic illness, it is natural for family members to revolve around the child. This can result in children, and eventually teens, becoming self-focused and even entitled. People just don't function well when they are the constant center of the universe.

   Helping teens learn that they are an important, contributing member of a family and society is a critical first step to helping them find meaning and purpose in their lives. There is something fulfilling to the soul about helping those who are less fortunate. Seeing that there are others who also suffer various misfortunes and hardships can help teens refocus their thoughts from, "Why me?" to "I can make a difference."

3. **Be positive and realistic at the same time.** I have found that most teens appreciate honest, straightforward, compassionate and gentle discussions about struggles and fears around illness. We all know it's there, but many people understandably have a hard time talking about the elephant in the room. However, when we face it and talk about it, it helps us and our teens cope with it.

   When teens expresses frustration about their illness, adults can take that opportunity to open up the lines of communication. Start by acknowledging the feelings and asking
exploratory questions rather than offering clichés and false assurances. After your teen feels heard, help brainstorm solutions to a problem he or she might be having or help him or her find a different mindset.

4. **Have everyone in the family practice gratitude.** Count your blessings out loud each day. Make it a family habit of keeping a gratitude journal and share it weekly over dinner or at a fun family get-together.

Parents are a powerful example for their children. Even if your teen won't participate, just hearing the little things that everyone else is grateful for can help to change his or her perspective little by little. If you are having a particularly hard time with your child, keep a gratitude journal about him or her. Then, share it. Words of love and encouragement can heal the hearts and souls of both the giver and receiver.

5. **Guide children and teens to focus on "being" rather than "doing."** Life tends to be defined by what we do, not necessarily who we are. The idea of achievement and excellence based on results starts early, from academics to sports to the quest (of many) for fame and fortune.

Don't get me wrong. I think achievements and excellence are great. However, when our self-worth, meaning and purpose in life are defined solely by these areas, it can be problematic. What happens when a child or teen doesn't excel or achieve? As parents and professionals, it's important that we guide our children and teens to fulfillment in life because of WHO they ARE, not WHAT they DO.

Young people with CF and other chronic illnesses need to be purposefully guided and supported in their development so that they base their self-worth not only on accomplishments, but also on who they are as a person (i.e., character strengths and virtues).

As parents, medical professionals and other caring adults who are involved with children and teens with chronic conditions, we can make a life-transforming difference by focusing as much on their mental health as we do on their physical health.