

# Keeping Hope ALIVE



Maintaining an attitude of gratitude while parenting children with cystic fibrosis.

by Lisa C. Greene

I pull into the carpool lane to pick up my kids from school and am yet again touched by the sight of a seeing-eye dog with a bright pink lunch pail hanging from her mouth as she trots alongside a young girl in a wheelchair.

And then there is the computer-generated voice that says “Amen!” at just the right moment during church. I am inspired by the family members in the front row as they minister to the physical and spiritual needs of their disabled son who is barely visible amidst the medical equipment surrounding him. While it must be difficult for them to attend church together, they return week after week.

How do special needs families keep their hope alive in the face of such daunting challenges?

I am no stranger to hope— or hopelessness for that matter. Both of our children were born with cystic fibrosis (CF). CF is a genetic disease that causes the mucous in the lungs to become thick and sticky, which causes lung infections, scar tissue and eventual lung failure. The median life-expectancy for those with CF is currently about 37 years, though it’s rapidly climbing due to advances in medical technology.

There is great hope for the future for people living with cystic fibrosis, and I am generally optimistic about my children’s future. But I know of a beautiful young lady who recently died from the disease at the tender age of 12. And the many pills, medical treatments and hospital visits that my two children endure serve as a bleak reminder of our race against time with this progressive disease.

Sometimes the icy fingers of hopelessness hide in the shadows around my heart, waiting for a beat to falter that enables them to enter. However, I don’t let hopelessness sneak in. I can’t. My chil-

dren depend on me. Not only am I their caregiver, I am also their role model. My children pick up on my cues as they learn to navigate their own way through a lifetime filled with the trials that their illness imposes on them. If I model hope, my children will be hopeful. If I model despair, then my children will be hopeless. How does my family keep our hope alive even when we don’t feel very hopeful? Throughout my “CF journey,” I have had many teachers encourage me, inspire me and lead the way. And I have noticed they all have one thing in common: gratitude.

A little research on gratitude turned up some interesting things. It is not clear why some people are naturally more positive than others. Perhaps it’s genetic. But it is clear that purposely focusing on what we are thankful for, instead of what we are upset about, helps us feel more optimistic about the future, as well as more loving, forgiving, joyful, healthy and hopeful.

“Because of my CF, I have received many gifts: resilience, closeness with loved ones, the amazing people one meets in the CF community, and the maturity and depth that living with a chronic and life-threatening disease can bring,” says Anabel Stenzel, co-author with twin sister Isabel of the book *The Power of Two* (University of Missouri Press). “Despite living with progressive lung disease that required me to have a lung transplant at age 28, I have learned, loved, seen, heard, eaten, walked, talked, touched, thanked, hoped and dreamed in my lifetime. And I have no regrets.”

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Stenzel personifies the positive power of counting one's blessings. And the good news is that such an attitude of gratitude is a choice. Anyone can be more thankful with a little awareness and effort. Here's how:

**1. Pay attention to your thoughts.** Make the decision to replace negative thoughts with positive ones. For example, say "I am thankful for having medical insurance" rather than "My insurance company is a hassle." Repeat affirmations over and over as necessary.

**2. Stay in the present.** What are you grateful for right now? Clean clothes? A loving family? Food on the table? Start with the simple things in life that we often take for granted.

**3. Take five minutes each day to meditate on one or two things for which you are thankful.** What blessings did today bring? A meaningful moment with a loved one? A beautiful sunset? A job well done? A word of encouragement given or received?

**4. Begin a gratitude journal.** Write down one different thing that you are thankful for each day for three weeks. Notice how much happier you feel after reflecting on your good fortune. Then, keep appreciating life's blessings.

**5. Share your blessings each day with your family, especially your children.** Ask family members what their blessings are, too. An attitude of gratitude is contagious.

Sometimes it can be difficult to muster the will to count our blessings. The following are some tips for keeping hope alive during challenging times.

- Keep your expectations reasonable. While hoping for a cure to a disease can keep us going, it can be devastating when no cure is found. Miracles can happen. Still, it's crucial to stay grounded in reality. Having faith with reasonable expectations helps us stay balanced.

- Take the time to grieve: Bad things happen. When they do, we understandably respond with shock, anger and despair. The path to acceptance is through encountering these emotions by allowing ourselves the time and space to grieve. The key is to find a balance and not get stuck.

Elise Free is a mother of a 2-year-old girl with CF who is nicknamed Froggy. "There are levels to my own grief," says Free. "One day I feel elation that Froggy lives in a time of progressive medicine, and in the next second, sorrow that we were so unlucky, then anger that our daughter has to suffer, and then guilt of being a carrier of a defective gene, passing on something dreadful to our child. And then there is the warm wash of gratefulness leading me to appreciate every moment with a monumental love powered by the knowledge that life is fragile and our time together is measured in breaths... And maybe that is the purpose of life: to find the balance, to accept the reality, but live in the hope."

When times are especially tough, we generally need something to hold on to—an anchor in the storm. We can find comfort in knowing that there is something bigger than us. We can find solace, believing there is some meaning and purpose for the suffering, even if we don't know what that might be.

How else do we parents of special needs children keep our hope alive? Marla, mother of sweet baby Emma who has cystic fibrosis, reveals: "I look at my daughter's face. Seeing her beautiful smile gives me hope."

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