

The Roller Coaster Ride

By *CHRISTINE KNAPP*

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We've all been there. Therapies are going well, our child is progressing, maybe we've even had a date night recently! Then, suddenly, your child gets sick again or starts having seizures, and you're back in the hospital, staring at machines, up all night worrying again...

It can be trying, and often I've found my exhaustion comes from not only being physically tired, but emotionally drained. The worry and fatigue set in, and it can become difficult to figure out how to keep moving in the right direction. Maybe you aren't sleeping well because your brain is on overdrive, or you're up in the middle of the night researching the next therapy or medication that might help your child.

During the back and forth, the ups and downs of the roller-coaster, it can be difficult to remain strong. The good and the bad and sometimes even, the

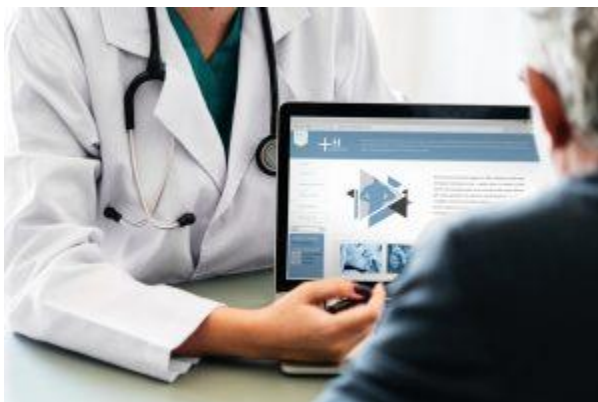
good *with* the bad, creep into our lives, and it's easy to just wish it away. How do you stay mentally solid during these difficult times, and perhaps, even happy?

Here are a few tips that have worked for me during my roller-coaster of a journey:



Sleep

I know, I know. Sleep is literally the last thing you probably want to do when you're up all night, hovering over your child in a cold, damp hospital room. I've literally curled up into a ball next to my baby and held him in my arms during some of these visits (and if you're anything like me, those hospital cribs are small with bars on the sides and are not memory foam, king size mattresses by any means). They've been the worst sleep of my life, but I want him to feel my arms around him and not be alone when he wakes up to a new place. However, I've found the best decisions I've made have been when I was able to think clearly, and my most emotional times are when I'm exhausted. While you may not want to sleep, it's so critical as parents that we take care of ourselves because we can't talk to the doctors and make instrumental decisions for our children if we aren't rested.



Ask Questions

I can't tell you how many times a doctor, therapist or insurance agent has given me an answer, and then I've asked more probing questions because I wasn't satisfied with the answer. We must be our child's advocate, and sometimes this means pushing the envelope in a way that may take us out of our comfort zone but allows our child to receive the best possible care. I've asked for the cleaning people in the hospital to stop coming to empty our trash at 9:00 p.m. at night while my child is fast asleep, I've questioned medication adjustments if I didn't believe the medication was working, and I've asked for different therapy times because they've conflicted with my child's naps and the time wasn't optimal. I've sought better answers to why insurance denied a claim, and I've appealed decisions that benefited us financially in the long run. While it may feel like all you are doing is constantly "fighting" others, I've told myself if I don't do it for my child, who will? If I'm not happy with an answer, I ask more questions. I feel better prepared to handle the ups and downs if I fully understand my options and the recommendations from the doctors.

- *Can we take this medication two times a day instead of one to see if it helps?*
- *Our prescription was denied? Why? Can you run the claim again?*
- *I can't apply to this study if my son has a history of seizures - are you sure? Can you ask your supervisor, because I didn't read that anywhere?*
- *What other strategies can we implement to encourage more speech?*
- *What research is out there that validates this decision? What is option B?*



Find Gratitude

This goes back to my earlier statement about accepting the good and the bad, but sometimes, the good *with* the bad. We may wait to be happy only during times that seem perfect, and I've realized that it's very rare to find a time with our children when things are perfect. My husband and I have started celebrating milestones that our son accomplishes because it helps us remember and appreciate his progress and how far we've come. When our son began taking his first steps, we went out to a fancy restaurant and sat for hours reminiscing about his journey to get here and how grateful we were for his progress. It was

important, because once you go home, you're thrown back into therapies and the next "goal" you want to reach, and it's easy to forget the goals already achieved. If you can, take a moment to find the gratitude and celebrate these victories, and then it's easier to remember these good moments when the difficult times arise. It helps put the challenge in perspective, and it helps to remember the accomplishments when there are new obstacles to overcome.

The roller-coaster of emotions as a special needs parent vary. A new milestone is reached, only to have a major setback. You move two steps forward, then one step back. But finding things to be thankful for every day, arming yourself with answers to the right questions, and making sure to get enough rest will hopefully provide you with the best tools possible to remain strong during trying times.

What other ways do you survive the roller-coaster of ups and downs in your life?

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CHRISTINE KNAPP

Writer, blogger and digital marketing specialist, Christine is the mama of her amazing perinatal stroke survivor. Her "why" is to continue to provide support and make sure no parent ever feels alone on his/her journey, and she began writing to give hope to other parents of children with special needs. Her son continues to grow and thrive, and you can follow their story on her [blog, Our Beautiful Hope](#) .

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