



# Who's Taking Care of You?

By Sabrina Johnson

**"I need you to come home as soon as you can," I sobbed to my husband.** Through my tears I assured him that the girls were okay, but that he needed to come home, that while nothing bad happened, I was not okay. That conversation was three summers ago – I call it my Epic Meltdown. I had reached a point of no return, and I have vowed to never return.

Life was business as usual for us that summer. My two girls were home, and it was a day of mishaps and chaos. I can't remember everything that went wrong that casual summer day. I put the girls down for a nap and sat in my living room trying to regroup. The tears soon turned to sobs. I was exhausted, run-down, out of shape and sad. Some of you can probably relate. But that

day was pivotal for me on my path of special needs parenting.

When my husband got home, my crying had eased and I told him everything. How my days were exhausting, there was always some emergency popping up that needed my attention, I was sleep deprived from interrupted sleep. He understood. He knew. After all, he lived in our house too. Here

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was the difference between us: I had let my new role consume me, he had not.

I said things to him out loud that I couldn't come to terms with inside. "I'm broken and I need help," I admitted quietly. We sat there and talked things through and devised a simple game plan to get through summer and ease some of my burdens. When fall arrived, I stayed true to my quest to turn things around. The answer was a year-long program through my church that helped me define who I am as a special needs parent, to remember my limitations, and who I am as a person. Not mom. Not wife. Not special needs parent. Just me.

What I realized during that year-long journey is that I was too busy trying to fix, do and make things right – all the time. My constant "doing" was not about my daughter Juliana's disability. The demands I put on myself were simply impossible. All my things needed to be done: therapy and doctor appointments had to be kept, add in a house with special diets for two children and there was no time left. Or so I thought.

We've all heard a version of the airline spiel given at the beginning of every flight, "In the unlikely event of a sudden loss of cabin pressure, oxygen masks will drop down from the panel above your head... Secure your own mask before helping others." That same advice should apply to parents when we are not flying. Perhaps the advice is more critical on the ground than in the air. For the rest of our lives, we have someone who will greatly depend on us; there is no way we can help anyone else, if we don't wear the mask FIRST.

When you know better, you do better. My goal now is to do and be better. Several weeks ago, I watched the sad face on my five-year-old as I headed for the door. "Mommy," she shouted, "I need to give you a hug. I wish I could go with you." I assured her that I would be back, that this is mommy's time to do something special for mommy."

I give myself that speech now at least twice a month. Sometimes, I don't even go out. I lay in my bed reading, writing or fiddling with my tablet while my husband gives the girls too much junk food and lets them

watch too much TV. It's my time to check-out and regroup, to put on my oxygen mask, and to remember that I can't lose myself again. There are a slew of things that need our time and attention, but 'ourselves' needs time and attention, too! I focused on: Who I am? Who do I hope to become? What do I love doing? What am I contributing? What brings me joy?

The next time you think that you don't have time for yourself, I hope you'll think of my Epic Meltdown. Then, think about these 5 ideas:

**Health.** When was the last time you put off a critical appointment for your son or daughter? Probably never. If I asked if you've put off an annual appointment for yourself your answer might be different. I want to be around for my daughters. I've realized that I increase the likelihood of that when I eat right, exercise and make my own medical care a priority too.

**Hobbies.** How would you spend a day if there were no constraints on your time? Yes, I know this is hard to imagine, but dream a little. What

things did you enjoy doing before you became a parent? Hobbies provide a release and an opportunity to experience things that make us smile or bring us joy. My husband loves to golf, I love to read and sew. We spend less time on hobbies now that we have children, but we both try to carve a little time for them.

**Home.** The saying goes that home is where the heart is. How's your heart (home)? Is it too full? Are there things spilling out of places that shouldn't be? I'm not talking about a white glove standard of home cleanliness, but your home should serve as a place of refuge and comfort. What I like most is that our home is cozy and filled with the girls' artwork and inexpensive treasures. I don't fuss over the little things but instead focus on keeping our house functional and safe for Juliana to navigate.

**Happiness.** This doesn't necessarily mean that every day you have the energy of a 25-year-old (unless you are indeed 25). I'm talking about that joy deep inside that reminds you of the good things you have. I keep my happiness

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# Looking Back at the FUN!



Aquarium Day



Aquarium Day



FOCUS on Moms  
West



FOCUS on Moms  
Atlanta



Under the Stars



Camp Infinity



# From A Nurse Volunteer

I'm a veteran nurse but new to nursing at FOCUS. During my week at Camp Hollywood I was amazed by the children's resilience and their joy! It was obvious to me that FOCUS parents were raising their children to be people who are as independent and self-sufficient as possible and who know how to give and receive love. I saw acts of kindness given to fellow campers, and these children felt secure in a new environment. Hats off to FOCUS parents, and thanks for the opportunity to care for your children.

– Elaine Harris, RN, MS, CCRN

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## Who's Taking Care of You?

brewing with my faith, family pictures and memories of good days and family events. What brings you joy?

**Handiwork.** Your work, or handiwork, is what you produce whether you work in or outside the home. Do you have a sense of satisfaction or contribution? Yes, getting paid is the end game, but there should be more, and I believe that work/life balance is important. That balance looks different for everyone. At the end of the day, a healthy dose of work reminds us that we have talents and skills.

Parenting a child with special needs is hard. But the road is harder when caregivers lose their way. I know, I was there. It took my Epic Meltdown to make me change. Now, I'm on a quest to keep myself on track with those 5H's that will help me be a better mom, wife, and person. I hope that they help you, too.

*Sabrina is a wife and mother of two who shares her new normal on her blog Juliana's Journal. She is the author of Forward, an e-book that helps navigate first-steps in special needs parenting. Visit [julianasjournal.com](http://julianasjournal.com) for more stories of encouragement and inspiration.*

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## Sibling Saves for FOCUS + Fragile Kids

her later about her gift – after the check-in traffic at camp died down. I wondered how this young girl with the sweet smile and shiny blond hair even knew that FOCUS and FOCUS kids might need money. "Abby," I asked later, "Why did you decide to give your money to FOCUS?"

Abby answered slowly and thoughtfully, "I see kids with special needs and read books about them, so I know they need help. At my church, they talk about helping others. I know FOCUS has camps for kids with special needs and decided that this would be my way to help.

"My sister Caroline [who has autism] is an inspiration to me. She's usually sweet, adorable, and even hilarious. So when she's in a bad mood, I try hard to make her happy again. She teaches me so much, and I'd rather have her than any other sister in the world. I often wonder what she's thinking, though. She speaks, but it's hard to understand her."

When asked if she had any advice for other FOCUS siblings, she said, "Sometimes your parents have to focus on their special child, and you may feel left out. You might think that you're not getting your fair share of attention. But you have to remember that your special sibling needs extra help, and your parents are doing the best they can to make time for you."

Observation, reading, and listening in church aren't Abby's only influences. "My dad shows me how to deal with others and with Caroline – and what to do when you can't deal with them," Abby giggles.

In a more serious tone, she says, "My mom is always busy – cooking, working, and taking care of four children. She reminds me that I have to do my part, play my role. And I try." Even at eleven, Abby Grayson is doing her part to be sure that FOCUS kids have the programs and help they need.

